COMMUNICATION IN UK OUTPATIENT ONCOLOGY CONSULTATIONS

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Abstract

This thesis is based on a sociological analysis of outpatient oncology consultations involving doctors and patients. Most patients have had surgery to remove their cancer. All have been referred for radiotherapy or chemotherapy and have been told on previous occasions that they have cancer.

I demonstrate how information about cancer is managed between doctors and patients. Analysis draws on some of the insights and principles of applied conversation analytic work. I report on a range of short and long transcribed data fragments, drawn from a tape-recorded data corpus. Whilst respecting the "autonomy" of the recorded data, I occasionally and informally draw on observations made during fieldwork to crystallize analytic claims. Analytic foci are derived from the natural unfolding of the consultation trajectory.

Three key topics are addressed: how doctors use history-taking to establish patient journeys to ascertain what patients know of their cancer; how diagnoses are embellished and treatment implications discussed; and how, within diagnostic and treatment talk, the participants negotiate the good, the bad and the uncertain character of the information shared.

I revisit the broad (and predominant) policy and research literature to confirm the benefits of conversation analytic work and the particular insights provided by this thesis. I also delineate some of the broader themes to emanate from the detailed analysis and challenge some common conceptualisations of "doctor-patient communication". Finally, I close with a discussion of the limitations of this thesis and possibilities for further work.

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Statement of Own Work

I have read and understood the London School of Hygiene and Tropical Medicine's definition of plagiarism and cheating given in the Research Degrees Handbook. I declare that this thesis is my own work, and that I have acknowledged all results and quotations from the published or unpublished work of other people.

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PART ONE - INTRODUCTION

PART ONE contains two introductory chapters. *Chapter One* offers the background for the thesis. It explains why I chose to focus on cancer consultations and introduces the theoretical and methodological context for the work. An outline of the thesis is also provided.

Chapter Two provides a natural history of my research. The chapter details how the study evolved and the methodological questions that were asked along that path are detailed. *Chapter Two* also provides an insight into the various literatures that were engaged during the early part of the thesis, as I was developing my research question.

1.

An introduction to this thesis

> [Sociologists should] acknowledge how knowledge is made, legitimated, shared and transmitted within socially organised contexts. One should bracket ontological problems of scientific and medical knowledge in order precisely to concentrate on their distribution, transmission, legitimation, representation and, generally their *production* in everyday settings of work.
>
> Atkinson, 1995: p46.

1.1 Introduction

This thesis is based on a sociological analysis of the outpatient oncology consultation with a particular focus on how information about cancer is shared between participants (doctors and patients). I report on a range of short and long transcribed data fragments, drawn from a tape-recorded data corpus. Analysis demonstrates some of the recurrent features, activities and organisations that inhere in the joint production and management of information-about-cancer, in the context of treatment-focused consultations.

The cancer consultations explored in this thesis are a mixture of first and second meetings between consultant oncologists and patients who have been told that they have cancer, (most) have had surgery to remove their cancer and have been referred for radiotherapy or chemotherapy. Hence, the main task of the consultations recorded is to discuss radiotherapy or chemotherapy with 'new' patients. I focus in particular on doctors and patients who have not met before.

With increasing acknowledgement of the importance of providing information for cancer patients, the outpatient consultation provides an interesting and important site for study. The reasons for this interest will become clear once the broader policy and research contexts are described, and the character of the outpatient oncology consultation explained.

1.2 Organisation of this chapter

In this chapter I introduce the study presented in this thesis. First, the broad policy (*Section 1.3*) and research contexts (*Section 1.4*) are considered. I suggest why, given the volume of research in the domain of cancer communication, this study was justified. I also briefly consider the nature of the cancer consultation (*Section 1.5*). Second, the ethnographic context of the study is outlined to contextualise the data presented (*Section 1.6*). Third, the study methodology and procedures followed are described, including details of the recruitment procedures, sample selection and study limitations (*Section 1.7*). Fourth, the aims and objectives of the research are noted (*Section 1.8*) and, finally, I provide an outline of the thesis (*Section 1.9*).

1.3 The broad policy context

Together with cardiovascular disease and mental health, cancer is one of the Department of Health's priorities (NHS Cancer Plan, 2000). Broadly, ongoing (re)-organisation tends to focus on expansion and reform. Recommendations centre on building capacity to manage and treat cancer more effectively, including diagnosis, referral, access, and implementing services that reflect a philosophy of 'patient centred' care. Part of this policy focus includes a commitment to cancer research, as signalled by the recent establishment of the National Cancer Research Network.

Government produced documents include the Calman-Hine report (1995) and, later, the Department of Health's Cancer Information Strategy (CIS) (2000). The Calman-Hine Report recommended networks of cancer care, reaching from primary care to cancer units. Cancer networks were identified as the organisational model for cancer services to implement the NHS Cancer Plan (2000).

The goal of providing full information to cancer patients is often conceptualised as one way of loosening 'information control' in medicine, presumed to be characteristic of previous decades. As well as the broader organisational changes, there has been specific mention (on many occasions) of the importance of 'patient centred care', 'communication' and 'information'.

> The development of cancer services should be *patient centred* and should take account of patients', families' and carers' views and preferences as well as those of professionals involved in cancer care... *Good communication* between professionals and patients is especially important.
>
> Calman-Hine Report, 1995: p6: My emphasis.

Later, the government led CIS recommendations supported Calman-Hine by incorporating a series of core aims, in which it is argued patients need:

(1) Access to information about prevention, screening, availability of services, advice.
(2) Fast, reliable communications about appointments, test results, care planning.
(3) Sensitive, appropriate information about diagnosis, prognosis and 'journey timetable'.
(4) Informed treatment decisions in partnership with health professionals.

As part of this, the CIS proposed, "measures to improve communication between health professionals and those affected by cancer, such as enhanced communication skills training" (NHS Information Authority, 2000; Document Reference No.: 2000-IA-262). The NHS Cancer Plan (September, 2000) also detailed service changes to improve the delivery of care. More recently the National Institute of Clinical Excellence (NICE) has developed a '*Supportive and Palliative Care Guidance*' (2004). This document made the provision of cancer information by health professionals mandatory and good communication was again highlighted as an integral part of the provision of cancer care.

Further recent evidence of the continued centrality of 'good communication', 'information provision' and the patient 'voice' was evidenced in the National Survey of NHS Cancer Patients (2002; undertaken by the independent National Centre for Social Research). The NHS commissioned survey is the first of a series of surveys, all of which aim to assess the quality of care, as reported by hospital patients; in this instance with one of six types of cancer. Over 65,000 cancer patients from 172 NHS Trusts in England completed and returned questionnaires.

The survey included approximately 100 questions that covered a range of topics relating to patients' experience of care. These included: information about the diagnosis, first treatment and discharge, and trust and confidence in clinicians.

Respondents were also asked to answer questions concerned to measure affective and process variables, such as the amount of dignity with which staff treated them and to what extent they were involved in decision making. Entire sections of the questionnaire focused on 'communication' and 'understanding' vis-à-vis diagnosis and treatment.

It is plain that policy research and service evaluations echo recognition of the importance of the individual "patient voice" and a related need to evaluate health service provision. The burgeoning number of policy documents dedicated to improving communication of information represents not a sudden shift in focus but (arguably) a fairly steady escalation of policy documents that have laid out the importance of patient views and their right to information. In terms of patient rights to information, originally published over a decade ago, the Patient's Charter (1995) detailed guidelines on what patients can expect from the NHS. The Charter itself has been both criticized and lauded. Critics have, for example, questioned the over-emphasis on aspects of quality that can be quantified, to the neglect of other, equally important, indicators of quality in patient care:

> Quantitative indicators are nearly always seized upon because they measure that which is measurable, rather than that which is significant.
>
> Hart, 1996.

Despite this and the suggested lack of clarity of the Charter, the rhetoric of patient involvement, user engagement and patient-centredness has been wholly embraced in the policy literature and continues to be central today; 'The NHS should put the patient at the centre of everything it does' (DH, 2004).

Contiguous with the policy drive to improve cancer care, including communication and information, research activity in the domain of cancer has witnessed somewhat of an explosion in the last ten years.

1.4 The broad research context

Over ten years ago the Audit Commission report on communication between patients and hospitals was influential in highlighting a range of problems encountered by people with cancer (1993). The centrality of the cancer consultation in research a further ten years on is revealed in a search of studies (grey and published) that have sought to examine patients' views of cancer and experiences of 'communication'. It seems that, at least on the surface, similar issues preoccupy researchers from differing disciplines today when compared to writers in the late 1950s and onwards (e.g. Balint, 1957; Byrne and Long, 1976; Freidson, 1970; Mishler, 1984; Parsons, 1951).

In terms of sociological work in the field, a review of the topics of all of the studies published in just one key sociology journal since the late 1970s, namely *Sociology of Health and Illness*, revealed a large (quite intimidating) general sociological literature that has, in various ways, sought to understand the medical encounter. Authors from other journals such as the *BMJ* and *Social Science and Medicine* have also drawn on established concepts in social science to examine the 'negotiation of meaning' between doctors and patients, 'shared-decision making' (Charles et al., 1997; 1999; 2000) or doctors' sensitivity to patients' 'life worlds' (Barry et al, 2001; Stevenson et al., 2000; Charles, 1999). A variety of methodologies have been employed to examine this intricate relationship, including, for example, critical discourse analysis (Barry et al., 2001), quantitative surveys to examine 'patient enablement' in the consultation (Howie et al., 1999) and experimental interventions to measure doctor behaviours and their impact on such features as "spontaneous patient talking time" (Langewitz et al., 2002).

In 1981 a collection of papers concerned with various forms of lay-expert interaction in the illness setting appeared in the *Sociology of Health and Illness.* The preface to the work presented could quite easily have been written today.

> This issue has been associated with an increasing policy orientation in the research. What [are] the conditions under which the most successful medical encounters [take] place (using criteria of success derived from the settings' participants)?
>
> Baruch et al., 1981: p251.

Importantly, the emphasis on "participants" tells a story about the approach taken by Baruch and colleagues. Theirs' was research not concerned with normative definitions of 'good' and 'bad' practice, but with that which is observably and demonstrably important to those *in* the medical encounter. This point is important in terms of the work that is presented in this thesis, and I shall return to this later.

How best to define or operationalize concepts like that of 'patient-centredness', 'user involvement', or 'good or bad' communication has presented a perennial problem (see Charles et al., 1999; Wilson, 1999; Coulter, 1999; Cleary, 1999; Williamson, 1999). Much research, however, seems opaque in its conceptualisations and recommendations. A focus group study conducted by the National Cancer Alliance (NCA) (1996) is just one case in point (and is frequently cited). Take the following conclusion on how patients should be told about their diagnosis:

> Obviously patients differ and some recognised the need for balance between false reassurance and unnecessary worry, but the most successful approach by health professionals seems to have been where patients were given a gentle hint of the consultant's concern before the final diagnosis was confirmed.
>
> NCA, 1996: p26.

The interactional accomplishment of 'gently hinting' before 'confirming' is nothing short of intriguing. My question on reading this, and other work like it, was always one of "does it occur and if so *how*?"

Although illuminating in some ways, a great majority of the communications and psycho-social oncology literature did not seem to capture adequately precisely how doctors should take up the challenge provided in documents like that produced by the NCA. Mostly because of this problem, this thesis eventually became distanced from higher order constructs such as 'good and bad communication' and 'patient participation' as contained in documents like those described. By contrast, a detailed look at what doctors and patients *do* in situ in the cancer consultation provided a preferable starting point for study.

Conversation Analytic (CA) work can and has provided a useful methodological key to examine the details of social action, including, of course, the medical meeting. Thus, listening to audio-recordings and reading transcribed talk provided a way of being able to explicate some of the features of the outpatient oncology consultation.

I do not want to talk at length about the opportunities provided by close analysis of conversation or talk-in-interaction. This has already been cogently documented, together with the methodological procedures and principles of Ethnomethodology (EM) and CA (see Psathas, 1995 for a brief introduction). Moreover, over the last thirty or so years, the reporting of a range of studies that have analysed sequences of talk has occasioned a body of applied conversation analytic work, which demonstrates the benefits of detailed analysis. Studies show how relatively small differences in behaviour can have 'profound implications' for diagnosis and treatment.

Researchers informed by conversation analytic work have attempted to 'come to terms with how it is that things come off' in this or that way' (Sacks, 1992: Part I, Volume I, Fall 1964, LC1: p11). Studies have examined sequences of talk in professional-client meetings in general (e.g. Heath, 1986, 1992; Peräkylä, 1995, 1998; Pilnick, 1998, 2002; Maynard, 1992, 2003; Silverman, 1987; 1997), and cancer meetings in particular (e.g. Beach, 2001, 2003; Lutfey and Maynard, 1998) in order to render "observable-reportable" or "storyable" (Sacks, 1992: Volume II, Part IV, Spring 1970, LC1: p218) a range of communicative practices. Conceptualising the medical meeting as a "speech event" in this way has "yielded" important insights (Frankel, 2001).

This body of work confirmed my decision to use the outpatient oncology consultation as a vehicle for examining the management / construction / negotiation of cancer related information. Alternative spaces could have been examined to study the management of information and communication, but the waiting rooms, informal meetings, or talk in the chemotherapy suite, for example, would not have so easily permitted a detailed examination. Moreover, the importance of the consultation was reported time again by the patients with whom I was speaking (Leydon et al., 2001a) and this fuelled a continued interest in the cancer consultation.

I was also aware of the vast literature that had sought to focus on the 'bad news interview'. A recent systematic review of work that has sought to understand patient views and experiences of cancer suggested that 'much of the research found for this review was concerned with the way in which the diagnosis of cancer was given or the bad news interview, as it has become known' (Commission for Health Improvement, Farrell, 2001). In part, the tendency of others to focus on the 'bad news' interview led me to focus on treatment-focused meetings, with patients who had already 'received' their diagnosis and whose cancer trajectories had already been set in motion.

Information sharing about a cancer diagnosis is accomplished in and through a series of interactional episodes, not limited to the 'bad news' interview (Farrell, 2001). Over time, the story of the cancer develops and can do for some time after the initial diagnosis. Following the first 'bad news' consultation, additional information is shared between doctors and patients, yet few have sought to understand these later meetings. For example, patients do not simply have cancer, but have cancer of a certain grade, stage, size, position, which has or has not metastasised and so forth and this information has to be shared. By moving beyond the 'bad news interview' I hoped to provide an aperture on the ongoing journey of the cancer patient. In the context of policy directives and more broadly an NHS now grounded in a philosophy of 'information for all', an examination of this particular information sharing space seemed to be timely and justified.

1.5 The cancer consultation: What role can it play?

The outpatient consultation is a main 'formal' space for the exchange of tailored information for patients[1]. Survey research suggests that patients value the consultation because it is where details that are particular to their own illness are obtained, including disease progression, diagnosis, prognosis and treatment (e.g. Farrell, 2001; Leydon et al., 2001). Unlike other medical meetings, such as those found in primary

[1] 'Unscheduled' information sharing occurred in numerous places within the hospitals in which I conducted the research for this thesis and my related interview research. For example, one day I was introducing myself to a patient and her husband in the waiting room of an outpatient clinic. The patient's consultant walked past and he began to announce news about her diagnosis. The news seemed to be *news for her* and deeply consequential in terms of her prognosis. In the end I offered the doctor and patient my interview room, if they wanted privacy. They accepted the offer and continued the 'impromptu consultation' in the private space of the office. These impromptu meetings are not so easily recorded and we return to the limitations of recorded data in *Chapter Eight*.

care settings (e.g. Heath, 1986; Peräkylä, 1998), the information shared in radiotherapy / chemotherapy treatment consultations is often detailed. In addition, because of the complexity of cancer as a disease, individual cases are often equivocal in nature. This equivocality produces potential difficulties for doctors and patients alike. Conducting research in cancer clinics for a few years prior to PhD registration gave me the impression that the information imparted (often based on hypotheticals when waiting for tests, for example) is *uncertain* and details of the cancer diagnosis itself are often imprecise. Comments like the following, for example, were common, "if there's no evidence of spread then survival will be..." or "providing the scans show evidence of the tumour shrinking, we can be happy with progress..." or "if the blood count is okay, we can proceed with treatment" and so forth. The first adjuvant treatment meetings offered me a window on the sharing of such information, of how it is produced and managed.

1.6 The ethnographic context

Data were gathered over a three-year period from a hospital in the South West (H1) and one in the Midlands (H2) (ESRC funded). The PhD is based on this ESRC data corpus. Later, I collected additional longitudinal audio recordings (funded separately by the Medical Research Council, hereafter MRC). The majority of MRC data were not ready to be included in this thesis, but the experience of recruitment and familiarisation with staff and clinic life informed the research more broadly. Moreover, it provided a way of informally testing out analytic ideas based on the ESRC corpus. The MRC recordings were again collected from the Midlands (H2) and a large London teaching hospital (H3). I draw on some of the MRC data, when I do so this is noted.

Concurrent with gathering the recordings I recruited patients to a separate interview study (some of whom were audio-recorded and some of whom were not). The interview data were peripheral to the main interest of the PhD and are not used in this thesis. The reasons for this focus are described in the Natural History (*Chapter Two*), but essentially it rested in my interest in social action and not in patient accounts of their illness experience.

Recruitment involved attendance at specified clinics, in accordance with the participating Consultants' schedules. The clinics varied in length, but all were over three hours and some ran to four. The volume of patients also varied between the hospitals.

H1

The first data collection site in the South West of England was a general district hospital with one Consultant Oncologist who, at the time of recording, ran clinics single-handed. Another hospital approximately one hour away had more facilities for treating cancer patients. The Oncologist specialised in breast and gastro-intestinal cancers.

H2

The hospital in the Midlands constituted the second site for data collection. The hospital was a teaching hospital. A team of Oncologists worked closely with specialist nurses and an information radiographer. The Consultant specialised in breast and head and neck cancers[2].

At H1 (and H3) the Consultant I recorded specialised in treating patients with chemotherapy. Patients attended the chemotherapy suite on a weekly basis and the treatment took a few hours. They attended for approximately a six-month period and usually met with the oncologists on a fortnightly basis to monitor their response to treatment. At H2 patients being treated with radiotherapy attended the hospital on a daily basis for approximately six weeks. On attendance they received their treatment, which took a matter of minutes. Patients met the Oncologist on a fortnightly basis to monitor their response to treatment[3].

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[2] *H3:* The hospital in London was recruited to the study much later (to augment the original data set, with a special interest in a longitudinal focus). The teaching hospital had a great deal of research activity and two of the research nurses were present in the clinics to monitor for new recruits and to follow up on those already recruited to their studies, most of which were drug trials. Data were not available while writing all data chapters. Where extracts are included from this corpus I indicate thus.

[3] As an aside, on returning to H2 for the MRC recordings, they had reorganised the outpatient appointment schedule so that patients see the Oncologist for the first meeting, followed immediately by the information specialist who then sees the patients for the remainder of their treatment, with the exception of the last consultation where the consultant oncologist meets with the patient to assess progress and to decide the next steps. These new 'information focused' meetings were recorded for the MRC study.

The waiting area of each hospital differed but essentially the areas were furnished with soft chairs placed against the walls, had information leaflets about cancer and various support and informational resources, and coffee making facilities nearby. Receptionists made new appointments and greeted attending patients. Clinic nurses instructed patients where to sit and weighed patients to ensure their weights were not adversely affected by the treatment (once it commenced). Magazines were provided for reading material, some patients read while others chatted with significant others and, more rarely, other patients. Waiting times were often long and complaints did occur. My role occasionally evolved into allaying patient anxieties when asked about the long waits and making coffee for the busy clinic staff. These two roles seemed a fair exchange for my recorded data, but did at times confuse the patients and some clinic nurses who assumed I was a doctor, as evidenced in their method of addressing me when asking questions.

As well as attending clinic to recruit patients, I sat in on some consultations (not those recorded). Observing in this way was sometimes an awkward role to inhabit, especially when invited behind the examination curtain to look at patients' mastectomy scars or reconstructions. I spent time in the chemotherapy suite and radiotherapy planning room to gain some insight into the treatment process and technologies employed. I attended staff meetings to present my work, so that staff would recognise me in clinic. Finally, I attended a couple of multi-disciplinary meetings, attended by oncologists, radiographers, pathologists, surgeons, specialist nurses and information specialists, where patients' cases were considered, at fast pace, and treatment disposals outlined.

Whilst my engagement with the people and spaces outlined provided invaluable insight into clinic life, the field notes made during the course of that engagement are not drawn on for the purposes of this thesis, nor are the interviews. I do, from time to time, draw on some insights, however, to augment my analytically grounded observations.

The next section outlines how I set up the study on communication in outpatient oncology clinics reported in this thesis.

1.7 The study

To recap, this thesis looks at social action in outpatient oncology consultations, through a detailed study of talk-in-interaction. This is informed by the work of the late Harvey Sacks and his call to just come to terms with how social order / sociality is accomplished and to do so by exploiting what is already being accomplished in everyday social settings; hence the focus on naturally occurring materials. Assumptions of what constitutes 'good communicative practice' are placed to one side to instead ask *what is going on and how is it produced*? This means that questions about the functions or dysfunctions of activity X or Y are suspended until the activities themselves are adequately understood and understood in their own terms.

Describing the research procedure requires a certain glossing of the experience of being in the 'field', the politics of the field and my broader observations at the time of data collection. That is, in a study that focuses on talk as captured on audio-recorded data, I do not systematically refer to the informal observations made during my time in the clinics, the time spent in peoples' homes or chatting with the health practitioners with whom I was engaged. The core focus is to explicate some of the communicative possibilities in outpatient oncology consultations: the 'production, transmission, receipt and legitimation' of cancer related information. In the Natural History (*Chapter Two*) I describe the journey of the research and in so doing introduce some of the broader issues related to collecting data. Still, however, I focus on the methodological and theoretical issues and avoid producing a 'confessional' tale of research; of when, for example, I cried when patients I knew died, or smiled when patients received good test results[4].

[4] Some might be critical of quarantining the 'emotional' elements of the research process, but I remain convinced that these experiences would not alter the substantive story of the research or, importantly, the analytic claims made in the data chapters. Instead, I opt to (honestly) present the unpolished methodological meanderings and practical problems on the way to starting and producing a credible research project, which is precisely what the Natural History chapter aims to do.

1.7.1 The hospitals

Site selection was informed by another study with which I was engaged. The latter study already involved two cancer departments and results have been published elsewhere (Leydon et al., 2000a, b, c; Leydon et al., 2001). One of these hospitals was a well-known London teaching hospital and at that time it seemed a more useful option to compare two provincial English hospitals (one teaching and one not). The decision to not use London hospitals was also influenced by a desire to not be 'London-centric' and the high level of trials being run at the London hospital I was working at. I simply did not wish to burden staff and patients with yet another study.

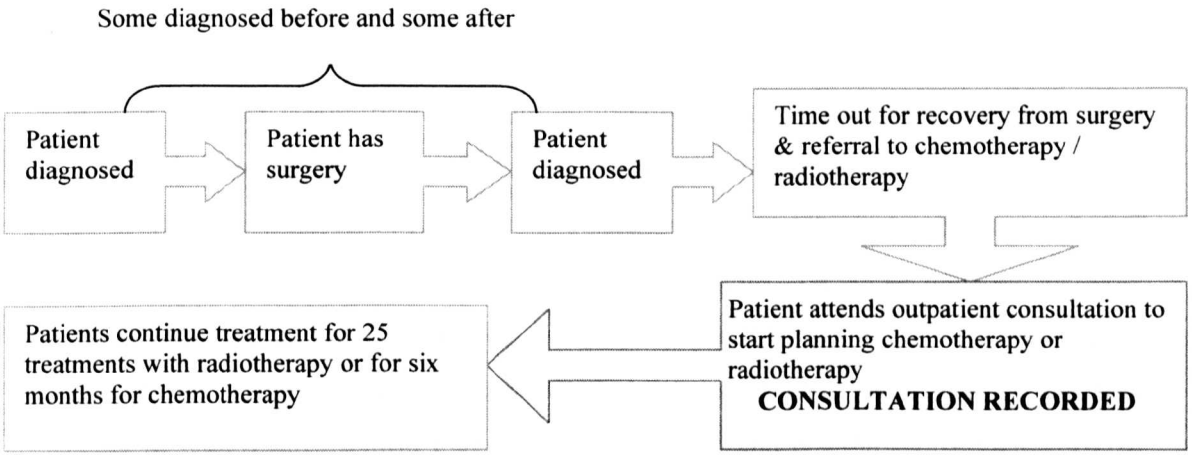
A colleague recommended two non-London based hospitals as 'research friendly' and the lead Consultants were approached. Two hospitals and two consultants, one from each, were selected. Pragmatic considerations informed the choice of just two Consultants. In this way, I decided it would be possible to track patient lists, travel to organise recruitment and engage fully with support and clinic staff to ensure recruitment proceeded smoothly.

1.7.2 The patient pathway

Here I want to mention the characteristics of the patients in terms of their place on the 'patient pathway' and the possible implications for their desire for and efforts to obtain information in the consultation space and more broadly the role those patients might play.

Most participants had been through surgery to remove their tumour and / or had been referred for adjuvant chemotherapy at Hospital 1 (H1) or radiotherapy (H2). Although diagnosis is often an incremental process that takes place over time, all participants estimated their date of diagnosis to give a proxy measure of how much time had elapsed since they entered the system as a 'cancer patient' and commencement of the study. The mean length of diagnosis to the date of recruitment was 54 days. To give some idea of the position of the patients on their 'care pathways', *Diagram 1* describes the journey generally followed by the recorded patients.

Diagram 1: The patient trajectory



1.7.3 Ethics

Once the hospitals were on board, I assembled ethics applications to the Local Research Ethics Committees (LRECs) and obtained visiting contracts at each hospital. Each LREC and the host institution (the London School of Hygiene and Tropical Medicine, hereafter LSHTM) offered study approval.

Although the recording of out patient consultations did not involve a change in care or treatment, the request for consent from patients may in itself be contentious. Patients, at a potentially vulnerable time, were being asked to help in a research project that may have little direct benefit for them (unlike, perhaps, in depth interviews, which offer an opportunity to talk through salient issues). Patients were assured that they could withdraw consent for the audiotape to be used in the study at any point. No patients withdrew (see *Appendix I* for 'Patient Consent Form').

Consultants identified patients who met the inclusion criteria (over 18 years of age, 'knew' their diagnosis, and were attending for their first or, if not possible, second consultation) from clinic lists. A standardised letter from the Consultant was sent to each individual patient. An information sheet (see *Appendix II* for 'Patient Information Sheet'), which informed potential participants about the study, accompanied the letter that told patients that their next consultation might be recorded. This provided patients with sufficient time to contemplate what was being

asked of them and maximised their ability to refuse participation without feeling uncomfortable for doing so.

On attendance at their next clinic appointment, the consent forms and information sheets were given to the relevant patients. Patients were asked to complete a brief background questionnaire to gather basic background details (see *Appendix III* for some of this information)[5]. Once the recording was complete, patients were asked if they would like a copy of their recording sent to them. Of those that did, patients reported listening to tapes, sometimes repeatedly so, alone or in the company of family and/or friends. The majority felt that having a tape recording of the first meeting in which information given is often detailed and complex provided a useful aide-memoiré. Although since I had provided the tapes it was perhaps difficult for patients to state otherwise. Tapes were collected at the end of each clinic and thank you letters sent to all participants.

1.7.4 Choosing the sample

As already noted, chance factors always influence the choice of sample in ethnographic work; the key issue is to show how they were accounted for in the research. Choosing patients was the more difficult of the selection tasks. The primary guide for recruitment of patients was a) patient stage of treatment, in particular that they had already been diagnosed with cancer and b) were attending clinic for their first treatment meeting. These information-rich cases (Patton, 1990: p169) would provide the opportunity to capture how two 'strangers' talk about cancer in first meetings and what kind of information is shared in adjuvant treatment meetings and how.

These criteria posed problems. The number of new patients attending the clinics was low. The majority of patients had already commenced treatment (radiotherapy or chemotherapy) or were attending for follow-up following discharge. Recruitment took longer than envisaged as a result and some of the patients recruited had met the Consultant before (when this is the case, it is highlighted).

[5] This was driven more by a requirement of the funding body and collaborators than any belief that I would be able to make comparisons according to face sheet variables such as age and gender.

In addition, the concerns of Consultants had to be taken in to consideration when deciding which patients to sample. One particular Consultant wanted a maximum variation sample to ensure that the eventual 'results' had the widest possible level of interest and applicability to other doctors. Similarly, the Consultant at H2 mentioned a need for more work on head and neck patients because of the seeming invisibility of this group of patients in the cancer information and communication literature. In this light, I selected a range of *politically relevant* cases. These included patients with breast, head and neck and gastrointestinal cancers (see Patton on 'Political Sampling', 1990: p180).

I visited successive cancer clinics on set days. Doctors and nurses were often too busy to set the recorder up, and this alone offered an insight into how time was a scarce resource in the busy clinic environment. Being present to carry out the recordings, however, provided the opportunity to make informal observations about clinic life, including the consultation itself.

Being in the clinic also proved information in terms of staff views on cancer services in general and on patients in particular. Their rationale for recommending one patient over another was often interesting, but did not necessarily influence who was recruited in the end. For example, some patients were considered difficult, others particularly shell-shocked and emotionally torn or extremely erudite and successful at seeking information, hence all interesting for my study. Their recommendations were presumably informed by everyday taken-for-granted knowledge of what factors might influence the level and type of information required by patients in a consultation and their understanding of the requirements of a researcher studying 'information management in oncology'. I reminded doctors that the only major requirement was the patient's stage on the illness path.

Twenty-eight[6] audio-recordings of 28 separate patients were collected from outpatient oncology radiotherapy and chemotherapy consultations. The reason for this number was informed on the whole by pragmatic considerations. The ESRC funding was just one year in length (Leydon and Green, 2001). Participants had breast, bowel or head

[6] One tape failure occurred, which left a total of 27 tapes.

and neck cancers. The age of participants ranged from 40 through to 80 years of age. More men than women were recruited and, in the end, this was largely explained by chance factors of who became available for recruitment on the appropriate clinic days.

Recordings were transcribed in full by drawing on standardised conversation analytic conventions (see *Appendix IV*).

1.7.5 Validity and generalisability

A policy of analytic inclusiveness ensured that initial collections of phenomena were broad. As analysis progressed, crude counts along the way provided a measure of the frequency of the activities described. Contrasting or unusual cases were sought and compared with recurrent activity types to test the robustness of emerging analytic ideas. The transparency of analytic claims and the search for contrasting cases hopefully permits confidence in the final analysis. Analytic integrity was upheld through close collaboration with colleagues and the sharing of analytic ideas during early analysis.

The observations made can only refer directly to the data corpus analysed, but observations do, in the end, resonate with other similar analyses that have sought to explicate how doctors and patients 'do' their work in the consultation. Hence, although not generalisable in the statistical sense, the analysis can be extrapolated in an analytic and theoretical sense.

In the end, there are numerous permutations or alternate actions available to particpants in any one consultation and as such this thesis shows something of what can (and generally does) happen. It documents some of the possible (recurrent) courses of action available to participants in an outpatient oncology consultation.

1.7.6 Some study limitations

The modest number of tape recordings limits what I can claim of the tacit social practices described in the following chapters. Studies that are influenced by the principles of conversation analysis usually draw on large-scale data corpora and the absence of such a wide-ranging data set here is limiting. Nevertheless, the availability of other data and reports of those data allows a certain confidence in the claims made.

Size of the data corpus aside, the number of doctors recorded might lead to questions of whether my observations can do anything more than comment on individual doctor styles. In the end, the analysis shows quite explicitly a range of interactional possibilities between doctors and patients. All doctors were working with NHS patients, and were meeting the patients for the first or second time.

In terms of both the doctors and patients recorded one could easily question how they might differ from those who were not recorded. The selection of doctors was based, in part, on colleagues' recommendations. These were largely grounded on my colleagues' understanding of their 'research friendly' nature. Fortunately, the advice was sound and the doctors gave their time. This approach to doctor selection begs the question, 'are those who were happy to participate examples of 'good doctors'; of those who are content with their communicative practice and broader organisation of patient care'? Indeed, this type of question should ordinarily be asked, especially in, for example, survey research. A recent study (Armstrong and Ashworth, 2000) persuaded the 30% or so of non-responders to a questionnaire to complete it following their initial refusal. The responses were then compared to the original respondents. Results revealed significant differences in the answers provided by the two groups of responders and initial refusuers. In short, the reported attitudes of the original responders versus the 'persuaded' responders varied. It might be asserted, then, that the practices of those doctors I recorded are also likely to differ to those doctors who might be less willing or unavailable to participate. The next question is, does this matter? The short answer to this is no!

This thesis explicates some communicative possibilities, it does not claim that these are exhaustive or to be found in all outpatient oncology consultations. I do not deal

with 'universals' but aim instead to sensitise readers to the alternative possible courses of action that are available to the participants observed. Moreover, the similarity of some of the findings with other germane work strengthens faith in that reported.

Other possible limitations related directly to my study are outlined in *Chapter Eight*. Some of the criticisms that have been levelled at work with a similar focus, mainly conversation analytic work, are dealt with in the Natural History (*Chapter Two*).

1.8 Aims and objectives

As already noted, the plethora of work in the domain of cancer communication immediately begs the question of why another study, such as that presented here?

The answer to this question is fairly straightforward. The majority of research in this domain does not attempt to elucidate the processes of information exchange at the level of interaction. This will be substantiated in *Chapter Two* and revisited in more detail in *Chapters Seven* and *Eight*. Moreover, researchers have had a tendency to focus on the so called 'bad news interview', when the initial diagnosis is delivered. The practices that contribute to the production and negotiation of information about cancer in early treatment consultations (radiotherapy or chemotherapy) have not been explored.

To recap, this study seeks to:

1. Describe the management of information in the cancer context, with special reference to first (or second) meetings that are organised to discuss adjuvant chemotherapy or radiotherapy.
2. Describe some of the practices that go towards the accomplishment of tasks along the consultation trajectory.
3. Produce analytic insights that can also speak to the interests and concerns of a number of practitioner audiences.

To this end, a number of particular practices and moments along the consultation trajectory are examined and these are briefly sketched in the outline of this thesis.

1.9 An outline of this thesis

In the data chapters that follow (*Chapter Three*, *Four*, *Five* and *Six*) some of the ways in which "members ongoingly produce social order" in the cancer consultation are explored by focusing on three core activities: History Taking, Diagnostic Embellishment and Treatment Talk. These broad 'headings' are, necessarily, glosses of the work that gets done, but act as a key to the work presented.

PART TWO

Chapters Three and Four: History Taking

In these chapters, I focus on the History Taking 'phase'. This was with a view to seeing how two 'strangers' (I focus on first meetings) – the patient and oncologist – get talking about cancer. It is well established in the literature that euphemism is a well-honed practice of doctors and patients alike. A recent report based on interviews with patients (CHI, December, 2001) quoted a patient as saying, "The first one to say "cancer" was the oncologist. The surgeon said "it's nasty, you've got to have chemotherapy", all that sort of thing, but he never said the word cancer". Quite how (indeed whether) this is the case in real-time interaction with patients, most of whom have already had surgery for their cancer and can be assumed to know of their cancer, remained to be seen. The chapter provides evidence of a caution in talking too

directly about cancer, but cancer is of course talked about and the chapter discusses how.

In the same report (CHI, 2001), the question of communication between health professionals was broached. Patients noted the difficulty of seeing multiple health professionals over time and ensuring that all know what is going on in their particular case. Doctors and patients can be working with incomplete information. This chapter provides a glimpse at how Oncologists get talking with patients who have had numerous discussions with other health professionals to which they are not directly privy.

PART THREE

Chapter Four and Five: Diagnostic and Treatment Talk

In these chapters the focus shifts to the next 'phases' when diagnoses are discussed and treatment disposals made clear. Generally, it is plain that the secondary care setting of outpatient oncology can involve the provision of a great deal of information that is often complex and extremely consequential for the patients with whom the information is being shared.

I examine when and how doctors recite the evidential basis for diagnosis and how they use this to inform or ground their treatment recommendations. The build towards the treatment disposal suggests a syllogistic / stepwise approach to information delivery. In addition, the way in which doctors package the information indicates a preference for providing some level of objectivity for the information being provided. That is, the 'voice of medicine' or 'collegial authority' is invoked in the doctors' evidential statements. Such objectivity hearably lends credibility to the information being shared. The volume and complexity of the evidence for treatment that is recited is interesting in its own right. The 'rules of etiquette' noted by Strong (1979) are invoked because patients are portrayed as allies who have come together in the consultation to "discuss a common cause" where "decisions [are] not imposed but discussed" (ibid: p. 100).

I demonstrate how in doing this informing there is an interesting cautious epistemics to the talk. When, for example, doctors deliver hearably 'bad news' about lymph nodes, some relatively 'good' information will be offered to counter or soften the negative. Two key organisations contribute to the accomplishment of the discussion of relatively good, bad and uncertain news and the invocation of an optimistic frame.

PART FOUR
Chapters Seven and Eight: Discussion

Following these data chapters, I discuss the relation of the observations contained within the thesis with the broader policy and research literatures. Although briefly touched upon in the Introduction (*Chapter One*) and Natural History (*Chapter Two*), I detail some of the particular gaps in predominant paradigms in the field of oncology and tender some suggestions regarding what exactly a conversation analytic influenced piece of work can add.

I also suggest some of the particular conversation analytic contributions and the broader themes to evolve out of the more detailed analytic observations. I discuss some (more) of the limitations of this particular thesis and future possibilities for further research.

In the next chapter, the evolution of the research is described, with special reference to the relevant methodological and theoretical issues encountered during the early stages.

2.

A natural history of the research: Getting started, stopping and starting again

2.1 Introduction

This chapter describes the evolution of the research reported in this thesis and some of the influences on that process. In so doing, the methodological and theoretical issues that were necessarily considered along the way are reported. Predictably, the journey to the here-and-now of writing the natural history of the research has been long and, at times, difficult. I include the most relevant aspects of that journey and in so doing produce what I hope is a reasonable summary of how this study evolved. As stated in *Chapter One*, this chapter is not a 'confessional', but discusses analytic and practical issues involved in the research process.

The evolution of the final study involved reading a broad literature concerned with information and communication in cancer. This included work published under the rubric of psycho-(social)-oncology and the sociology of health and illness. Originally, I read around broad domains of interest including patient experiences and accounts of having cancer; doctor-patient interaction, which alone is large, psychological issues, quality of life and adjustment to diagnosis, the evidence on training doctors to communicate information more effectively and I engaged in the parallel methodological and theoretical debates.

A step-by-step appraisal of the broad literature read during the course of study carried a risk of providing an unnecessarily protracted read. In place of the conventional Literature Review Chapter, I opted to tell the *story* of the research and in so doing describe some of the literature that left an impression on me – *good* and *bad*, and which encouraged me to ask the questions that I eventually came to ask. To impose a structured description of *my*

literature retrospectively would have failed to capture adequately a more 'honest' and oftentimes-chaotic journey toward achieving a coherent topic and analytic approach, and in being able to nest the problem in an apposite literature.

As well as situating the research in a broader context, I attempt to situate myself as an audience of the literature and explain how my reading of *'it'* led to the work reported on the following pages. In so doing, the constraints or limitations imposed by alternate analytic approaches are raised. The resulting critique is not intended to attack the utility of work already undertaken in the broad research domain of cancer, information and communication, but to demonstrate my rationale for choosing one way over another.

In providing a Natural History Chapter in place of a Literature Review, the insights and influences of other literatures are still drawn on at relevant points. Moreover, in line with a qualitative approach to data analysis, reference to the literature occurs throughout the data chapters to augment and illuminate the points conveyed. In short, the thesis engages with relevant literatures throughout, and not in a single chapter (Silverman, 2000).

2.2 Organisation of this chapter

In the pages that follow, I introduce how I 'got started' (*Section 2.3*). This includes detailing the study that I originally undertook that was to form the focus of my PhD. Although the original project later became tangential to the final PhD study, it was this that encouraged me to ask a quite different question to that initially posed. In describing these early beginnings I introduce the literature, theory and methodology with which I was necessarily engaged. Again, these approaches became tangential to the final PhD topic and my methodological approach, and meant that the PhD study 'stopped' (*Section 2.4*) for some time. I provide a couple of core examples of why I was discontented with the original methodology and offer up a rationale for the eventual PhD project.

Next I present how I 'got started again' (*Section 2.5*) and developed a study which could move me away from "using informants" to 'building a natural study' and the key

transformations that that entailed. Included in these details are the very act of learning how to analyse naturally occurring materials (*Section 2.5.1*), and how to place to one side assumptions and concepts gleaned from my reading during the original project. I consider some (more) thoughts on the kind of patients I had recorded in terms of their place on their illness trajectory (*Section 2.5.2*) and the possible consequences for the amount of information that they might require and consequent efforts made during the consultation space to ask questions or enquire for further information. Finally, in relation to my final research topic (*Section 2.6*) I present some of the core criticisms levelled at work that draws on conversation analytic techniques and principles and tender some counter arguments. The chapter closes with a Summary (*Section 2.7*) before proceeding to the first data chapter, *Chapter Three*.

2.3 Getting started

From *Chapter One*, it should be plain that a Sacksian approach of just trying to "come to terms with how it is that the thing comes off" (Sacks, 1992: Volume I, Part I, Fall 1964-Spring 1965, LC1: p11) informs the work presented. It took some years to reach this point.

In 1998 I assumed a position as a Research Fellow at the London School of Hygiene and Tropical Medicine (LSHTM) to work on a three year Cancer Research Campaign (CRC) funded project and this became known as, "A Patient Information Study: The information preferences of people with cancer" (Leydon et al., 2001). The study was funded for three years and I registered for a PhD. The original aim (as outlined by the PI and funding body) was to assess qualitatively and quantitatively the level of met and unmet need in cancer patients across the UK. Fieldwork commenced, which included patient interviews, focus groups and a postal questionnaire, in that order[1]. It was clear that prior to the research commencing, the way in which the research question had been framed carried

[1] In total 18 in-depth interviews were conducted, three focus groups and 365 questionnaires completed. The main findings have been published elsewhere (Leydon et al., 2000a, b, c,; Leydon et al., 2001). Please see the back pocket.

with it a set of assumptions. In particular, the emphasis was on understanding 'unmet' needs of patients, which implied *inadequate information provision* and *poor communication of information* in cancer.

Although it was clear that a substantial literature had delineated core problems in this area of practice (see *Chapter One*), I was concerned that to begin a PhD with a clear set of aims, a study design, methodological slant, and definition of the problem, would preclude the opportunity to ask and pursue emerging questions, which might be orthogonal to the original scope.

The literature that I was initially directed to offered core domains of investigation; 'lack of information' and 'poor communication', different methods used for information giving, and training interventions in communication skills. Broadly, the research originally identified aimed to evaluate the current state of *information in cancer* and out of this came *corrective* or instructional trials and training programmes, with improved ways of *providing information.* Although these literatures later became tangential to the PhD study, in the beginning they were critical reading.

2.3.1 Coming to terms with and placing to one side the psychosocial oncology literature

During the first year of the CRC funded project, a policy or gold standard of 'information for all' emerged from the literature and policy directives. Survey studies generally reported that over 80% of patients want to know if their illness is cancer, and between 70% and 94% want full information whether good or bad (Hearn and Higginson, 1997). Once patients know their diagnosis, the majority want to know about treatments, investigations and side effects. Two broad problems evolved from this literature.

First, while I accepted and endorsed the line that all patients have a *right* to information and that some patients might not receive the information that they desire, patient accounts from the interviews I was conducting, as a part of the CRC project, did not unequivocally

invoke the importance of 'information' I became interested in the possibility that not *all* patients want information or if they do not at the times predicted (see *2.3.2*). Second, the studies engaged in assessing information need and information 'giving', whilst useful, did not seem to offer a view of the processes involved with the giving, receiving and sharing of cancer related information. I discuss the second of these two broad problems in *Section 2.4*. Let us first deal with the assumption that *information* is an intrinsic good.

2.3.2 Information as a panacea

My earlier research also examined the idea reported in survey data that "all patients want as much information as possible" (e.g. Meredith et al., 1996; Jenkins et al., 2001). Pilot interviews with cancer patients highlighted ambivalence in regard to what to know, what not to know, when to know it and how to find it out.

> The thing with these leaflets, I mean I did start to read a few, but then when you read them you get information, but I think they give you a bit too much about what it's going to do and where it can go. I know I have it and that's all I want to know, you can know too much.
>
> [60-year-old man with liver cancer].

Interview data revealed moments on the illness path when, as Pinder found with her study of people with Parkinsons, information might not be "the priceless resource many writers suggest" (Pinder, 1990). 'Hope' was constructed as the sine qua non of surviving or managing a cancer diagnosis and this interacted with information seeking in complex ways. At times, it meant avid searching for information, while at others 'hope' was achieved through limited searching for, or active avoidance of, new information. Ruth Pinder in her study of Parkinson's disease said of this:

> ...Knowledge was not seen as a means of alleviating anxiety. Patients preferred the uncertainty of not knowing, because it was this uncertainty which gave them hope.
>
> Pinder, 1990: p33.

Periods of self-censorship functioned to preserve hope by avoiding negative information about the likely trajectory of their cancer and in turn helped to manage their fears associated with the potential of a negative outcome (e.g. lack of cure, treatment success).

> In the end I got so confused and one woman had such an influence on me that I was moving very fast in the direction of thinking I would have chemotherapy and I wasn't too keen to get too much input that was going to suggest I shouldn't. I think I consciously censored myself. I didn't look chemotherapy up on the Internet...
>
> [48-year-old woman with breast cancer].

The status of interview data is contested in the methodological literature. To say nothing of how I was going to treat my interview data[2], initial analysis turned to the double-edged nature of information, of how sometimes it would be jettisoned in favour of 'silence' (see Moynihan, 1998 for a discussion of 'strength in silence'), or how it could provide too much detail at a time when detail was not desired (see Silverman, 1987). The focus on the possible problems encountered by those who do receive or access information, and how sometimes it would be unhelpful to *some* patients, sat uncomfortably with the increasing policy and research trend of viewing information as a panacea and as a pre-requisite to a less difficult cancer journey.

In similar vein, analysis of illness narratives of women with newly diagnosed breast cancer suggested that women can 'feel' a pressure to break down in the bad news consultation because of cues and signals about the need for support (Morris, 1998). Patients responded in interview by saying that they do not always want to break down or 'switch on the crocodile tears'. Wilkinson and Kitzinger's (2000) focus group study with

[2] Interviews are a popular device used in social research as applied to health. For some time the merits of the interview have been debated and the status any one researcher should confer on data collected has been discussed. Some have criticised those who believe in the ability to tap into an authentic version of the world of the interviewee. This straightforward link from 'inside' to 'outside' of the interview situation belies the complexity of human interaction and the art of telling an illness story. A dual track approach is possible (Silverman, 2001). Glassner and Loughlin used such an approach in their study of adolescents' perceptions and uses of drugs (1987). They treated interview data as both culturally defined narratives and as possibly factually correct statements (see Silverman for discussion of this 'dual track approach', 2001). Some might argue that to do both carries a large risk of doing 'both' badly, but in the world of applied social research and the vagaries of funding pressures and diverse agendas, this is one solution.

women with breast cancer also found that women used optimistic statements as maxims and put them in the voice of 'you', designed to generate agreement. This work clearly demonstrated the danger of treating what respondents say as direct expressions of their experience and I was concerned that the study's question of 'information need and communication' might be at odds with the methodological approach chosen.

Nevertheless, my early analysis of interviews seemed to present a plausible story about the double binds of providing a warrant for patients to speak about their feelings and the reticence among *some* patients to confront information at *some* points along the cancer 'journey'. This, when combined with the opacity of comments like, "79% (95% confidence interval 73% to 84%) of patients wanted as much information as possible" (Meredith, 1996), led me to reconsider what I might want the project and the PhD to be about.

In addition, the CRC project interviews I was conducting suggested that the process of knowing a diagnosis is incremental. As suggested in *Chapter One*, more often than not research focused on *the* 'bad news interview' (Farrell, 2001) as the defining moment and the most important space of information exchange, but the diagnostic process and peoples' experiences of the lead up to a cancer diagnosis led me to question this static and linear version of the 'cancer journey' (Leydon et al., 2003). In keeping with this linear view, information need in the cancer context seemed to be framed around the bad news consultation and events thereafter (Farrell, 2001). By contrast, my interviews suggested a need to extend the classical formulation of the illness 'trajectory', as '*diagnosis-through-to-death*', to encompass and routinely consider '*pre-diagnostic*' experiences, when people suspect cancer. Milliken and Northcott's (1996) conclusion based on a study of hypothyroidism that, "the trajectory is already in motion before a diagnosis is made, and ... this pre-diagnosis phase of problematic symptoms may be lengthy" (1996: p203) resonated with my early analysis (Leydon et al., 2001).

For example, when I asked one interviewee to report her diagnosis date on a pre-interview questionnaire, she said she could not complete the questionnaire. When I asked why not she replied:

> It's not one specific time because you are dealing with different people they don't know what you have been told by anybody else, so that actually knowing what is wrong is a gradual thing, it's incremental. Somebody will tell you something and then you have to find out from somebody else more details and then you have to get to yet another person to find out what's going to be happening.
>
> [ID: 13, 1-11; 60-year-old bladder cancer].

The question of the timing of the diagnosis and clarity of diagnostic knowledge clearly raised a number of issues for interviewees, some of which were related to information and support at this early time. Patients often remembered the first mention of the word cancer and precise details of time, place and date were recalled, but the actual process of knowing and being fully cognisant could be a gradual and "incremental" process over time.

I also became interested in definitions of normality and entry and exit criteria for the categories of health and unhealth (Tishelman and Sachs, 1998: p55). Sickness, as talked about in interviews, was not just about symptoms and bodily change, but also about external, professional recognition that bodily manifestations are non-normal and hence worth pursuing and diagnosing.

These early results fostered an interest in how information is communicated with special reference to points on the illness path other than the 'bad news' interview, including the pre-diagnostic stages of the cancer journey and those moments after the 'bad news interview'. How do patients and doctors interact and what information gets shared prior to a diagnosis and later, once a diagnosis has been offered?

The communication and seeking of information after the 'bad news interview' provided an alternative possible focus. Logically, it also seemed that the information sharing when

patients are referred for adjuvant treatment would be an area worth investigating[3]. The patient views I was collecting via interviews, focus groups and questionnaires would not permit such a focus. They were not 'an appropriate substitute for the observation of actual behaviour' (Heritage, 1984: p236).

2.4 Stopping...

> Had I realised at the outset it would take two years of constant effort to get [funding and time], I might have returned to the problem of whether it was all worthwhile. But fortunately ignorance stood me in good stead and I began to learn the art of grovelling for funds.
>
> Barley, 1986: p13.

Two years into the research there was no research topic appropriate for a PhD. I knew what I did not want to do and the literatures I did not wish to engage with any further had become clear. I was, however, constrained by funding directives and deliverables with clear requirements. At this point I published a paper based on the pilot in-depth interviews to document the double-edged nature of 'information' (Leydon et al., 2000a,b)[4]. Responses were favourable overall and the greatest accolades came from positive patient responses. However, one survey study, published shortly afterwards, reinforced the importance of information to patients[5].

In this paper by Jenkins and colleagues (2001) a direct comparison was made in the opening paragraph between their 'very large sample' and my 'very small qualitative study' with 'contrasting results'. It was my first unintended foray into what 'felt' like an

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[3] A recent review of women with breast cancer concluded that the core patient preference is for verbal information to be provided by a health professional (Rees and Bath, 2000).

[4] Co-authored with members of the steering group: C Moynihan, K McPherson, A Jones, M Boulton, J Mossman, and M Boudioni.

[5] Results showed that, "87% (2027) wanted all possible information, both good and bad news" and the authors concluded, "the results from this very large sample provide conclusive evidence that the vast majority of patients with cancer want a great deal of specific information concerning their illness and treatment. Failure to disclose such information on the grounds that significant numbers of patients prefer not to know is untenable" (Jenkins et al., 2001).

academic scuffle. This negative (academic) reception of early work provided a lesson on how my attempt to examine patient information 'need' and patient 'information seeking styles' through in-depth interviews, might not be the best way to approach the question of how information is managed in oncology. A rapid response from 'breast cancer survivors and consumer advocates' further magnified how the paper provided a view that was not only derived from a 'very small' qualitative analysis, but a study that provided thoughts that were contra common thinking on the subject.

> ... We know only too well the trauma associated with a diagnosis of cancer. With this background we find the study by Leydon et al disturbing and disappointing... there is evidence showing that virtually all patients have a deep-seated need for specific information.
>
> Lockwood and Manaszewicz, 2000[6].

Regrettably, it seemed that our reporting of the ambiguity of information seeking and need, and the reasonableness of those *few* patients who *choose* no or limited information was interpreted as a regressive step in the psychosocial oncology field. Notwithstanding, it still seemed to be the case that at worst those who do not seek to augment their knowledge of their illness were somehow counted as intellectually deficient (aka working class), besieged by misunderstanding or in denial, "hopeless or helpless". At best these 'few' were considered unusual 'outliers', the odd five or ten per cent[7].

Interviews, then, had provided a way of thinking through the problems in the research domain of communication and information in cancer, and had contributed insights into people's feelings about information. This work, however, only alluded to how information was provided and sought and as Stimson and Webb (1975) showed some time ago, in their example of patients speaking to other patients about their role in the

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[6] See authors reply in Leydon et al., 2000c.

[7] Contra this thinking, Mike Michael's comments seemed fitting:

> In some cases scientific knowledge is bracketed, ignored, jettisoned or avoided because it is essentially peripheral to or may even obscure the real issue, 'ignorance' is a deliberate choice.
>
> Michael, 1996.

consultation, the 'story' provided a 'vehicle' for my interviewees to offer a version of events. The stories themselves might have had little relevance to the phenomenon of interest, in my case, the communication of cancer related information following a diagnosis. Later, in similar vein, Baruch (1981) showed how the space of the interview could be used not just as a site for 'relaying facts' but for building a story in which the speaker 'comes off in a morally adequate light'. In my interviews, I was asking patients how they felt about the consultation, what sort of information got shared, how much they participated and so forth. While their answers were interesting, especially in a context where information seeking is generally considered a *good* patient practice, they did not provide information on the issues with which I had become most interested; 'how do doctors and patients work together in the consultation'?

2.4.1 *Broad-brush evaluation vs. detailed explication: Capturing the process*

Whilst it seemed obvious that the broad-brush evaluation others and I were undertaking, combined with qualitative work, was useful for outlining areas of potential need, it did have a strong sense that I was 'talking around' the issues of concern and the phenomenon was 'escaping' (Silverman, 1987). An introduction to Ethnomethodology during the completion of an MA in Qualitative Research at Goldsmiths' College, University of London, had made clear the utility of looking at what people '*do*'. The focus on 'doing' underpinned my growing interest in understanding the *practice of communication,* and in what *constituted information* and this fuelled a distancing from wishing to ask what people think about communication and information. The methodological problematic of not adequately being able to access patients' "unspoken stocks of knowledge" about the management of information left me with "a sense of how the world [of oncology] works, but without its detailed explication" (Schegloff, 1992: p106)[8]. Moreover, patient stories

[8] "The trouble with their work [Anthropologists] is that they're using informants; that is, they're asking questions of their subjects. That means that they're studying the categories that Members use, to be sure, except at this point they are not investigating their categories by attempting to find them in the activities in which they're employed" (Sacks, 1992, Part I, LC 4: p27). Although of a critical vein, Sacks also stated that to criticize is to acknowledge that work is worth something in the first place, "where criticizing is giving some dignity to something" and I do agree with this outlook (Sacks, 1992, Part I, LC 4: p27).

were just that and my interest in how any one story was 'worked up for the occasion'[9] would not help with my central task of coming to terms with how information is managed at the level of interaction. Looking at the procedures for telling stories, rather than their content, would not bring me any nearer to understanding how it is that information about cancer is shared. Hence, whilst it was appealing in the early stages to choose a similar path to that chosen by authors like Wilkinson and Kitzinger (2000) to examine my interview data, the revised research problem would not get answered in this way.

2.4.2 *Information and communication in cancer: Notions of good and bad*

As well as the frequent *glossing* of the problem of what it is patients might wish to know and when, prior theorisations of what constitutes 'good' information management or communication often seemed to cloud descriptions of practice, as briefly noted in *Chapter One*[10]. Discussions of 'good' and 'bad' are common in the health literature in general and continue to be reported in the academic literature.

> *Good communication* featured as an essential component of personal care, especially from the recipients' viewpoint. If GPs and other practice members wish to focus on developing personal care, *developing communication skills* would be an important step.
>
> Tarrant et al., 2003

Good communication in the case above was not explicated in any way. In the field of oncology, *good* is routinely described as equal, facilitative, open ended, supportive, and

---

[9] Following Sacks' perspective, stories are "'worked up' for the interaction in which they're delivered". You might tell the same story differently for different persons, or on different occasions (1992: Volume I, Part VII, Spring 1968: p790).

[10] A brief quote from an editorial written by a medical oncologist on communication skills further elucidates how the phenomenon of interest (communication/information) escapes and how the assumption is that training is a) required and b) offers a straightforward solution to communicative difficulties.

> We take for granted our own communication abilities in history taking, but further training can enhance our ability to diagnose and treat conditions...
>
> Buckman, 2002.

Buckman's comment highlights the taken-for-granted nature of what people do, but instead of suggesting a closer look at what 'people do' he suggests further training. The issue of training is returned to a little later.

patient centred and these concepts frequent policy documents and other studies in the field (see *Chapter One*). Using a recent review article, which described key communication skills for a face-to-face consultation and how to acquire them (see Maguire and Pitceathly, 2002), Car and Sheikh (2003) developed a list of skills that 'can be applied to telephone consultations'.

Acquiring skills for telephone communication
Training in telephone consultation skills should focus on:

1. Active listening and detailed history taking
2. Frequent clarifying and paraphrasing (to ensure that the messages have been got across in both directions)
3. Picking up cues (such as pace, pauses, change in voice intonation)
4. Offering opportunities to ask questions
5. Offering patient education
6. Documentation

[Source: Car and Sheikh, 2003]

Again, I found the opacity of what lists like these refer to in interactional and practice terms frustrating. What, for example, might 'active listening', 'frequent clarifying and paraphrasing' sound or look like in practice? Were the telephone calls studied at all? Where is the demonstration that these particular skills have positive interactional consequences? Moreover, the patients seemed to be 'missing'. The problem of separating doctors' actions from those of their co-participants / patients is made clear from reading conversation analytic work and methodology texts. For example, Drew et al. (2001) demonstrate that that doctor's 'turn design is responsive' to what their interlocutor says or does. Patients' talk has consequences for how a trajectory of interaction plays out (these issues are dealt with in greater detail in *Chapter Seven*).

Reading conversation analytic work helped me to decide how I might distance myself from work like that above and what approach I might fruitfully take, time and data permitting. A comment by Silverman (1993) made particular sense, "researchers ought

not to begin from normative standards of 'good' and 'bad' communication" but should instead focus on "the *skills* that participants deploy and the *functions* of the communication patterns that are discovered" (p192)[11].

Following this custom, the opportunity to examine that which already occurs and, as far as possible, without thinking too much about what I or anyone else might consider to be good or bad offered a more satisfying alternative and provided good reason for a parting of the 'methodological' ways.

> Descriptions might be thought of as those of a keyhole observer who puts aside much of what he knows in common with the subjects about the scenes he is looking at, as if the writer had witnessed the scenes under a mild amnesia for his common sense knowledge of social structures.
>
> Garfinkel, 1967: p45.

[11] To be fair those involved in the 'communications industry' in oncology and training programmes do sometimes exploit the utility of naturally occurring material for training purposes. The two following quotes are evidence of this:

"Trainers should demonstrate key skills in action with audiotapes or videotapes of real consultations. The participants should discuss the impact of these skills on the patient and doctor"

Maguire and Pitceathly, 2002.

"Video recordings of patients (or actors) in a clinical consultation are a valuable way to raise awareness. Students can observe patients' concerns and suggest where the clinician could have enhanced his or her communication. We have used a video of women describing their experiences when undergoing screening for Down's syndrome and open neural tube defects in pregnancy. After watching the video the students can explore different ways of discussing risk with patients and presenting test results in ways that are helpful."

Sedgwick and Hall, 2003.

Rather, the sorts of details provided by naturally occurring materials are (generally) omitted in the reporting of such an enterprise, so Sacks' call to use data in such a way as to make visible for others how things are accomplished is not adhered to.

2.5 Starting again: From "using informants" to 'building a natural study'

> Social activities are observable; you can see them all around you, and you can write them down... If you think you can see it that means we can build an observational study, and we can build a natural study.
>
> Sacks, 1992: Volume I, Part 1, LC 4: p28.

Reading the literature had encouraged a different research question to emerge. My MA at Goldsmiths' College had taught me the power of observation. Goffman's observations on the 'interaction order' provided a memorable introduction to how insightful a look at the everyday could be (albeit often through the use of 'epitomizing vignettes'). Whilst Goffman's writings did not provide techniques that could easily be translated into a piece of systematic research, a CA influenced approach offered a practical-methodological answer to his recommendation to examine interaction as it occurs in naturally occurring settings (see Psathas, 1995).

My change in focus culminated in an application for funding and engagement with a literature to which I was introduced during my MA some seven or eight years earlier; to name a few, Sacks' (1992), Garfinkel (1967), Silverman (1987), Heath (1986) and Peräkylä (1991). Fortunately, concurrent with the CRC project, in 2000 the ESRC funded a pilot study to collect and examine audio-recordings from outpatient oncology consultations and the research reported in this thesis builds on that one-year pilot project[12]. Audio recordings would offer a view, albeit a snap shot view, of how doctors and patients manage and negotiate information about cancer and its treatment, in the naturally occurring occasion of the consultation.

To clarify 'Why a conversation analytic informed approach?' it is worth citing Psathas at length:

[12] I was also fortunate in persuading two academics to supervise me, one of whom had already retired.

> ...[W]e have carefully avoided formulations that employ the vocabularies and theoretical perspectives conventionally used in sociological studies of organizations, for example, roles, norms, status, control, authority, hierarchy, and so on, and any theoretical/explanatory schemas. The respecification of the problem of social order by Ethnomethodology and Conversation Analysis argues instead for a focus on the ways in which practical actions in any setting are organized, in what ways members orient their actions to each other, within the practical constraints such actions produce. Social actions occur in a context, the context provided by prior and next actions, the presence of others, the formulations and reformulations of meanings, of what has been (or is about to be) done.... the task is to show the inter-relatedness of social order and social action and then explicate this, not explain it.
>
> Psathas, 1995: p65-66.

Once I had decided what I wanted to do, had obtained the funding and started to transcribe and analyse the data being collected, the job of analysis could commence.

2.5.1 Learning to analyse data

> ...Find what the natural world may be 'telling you' that you did not know before, that you had not thought about that way before, that you had not entertained before – rather than to find which thing you already know...
>
> Schegloff, 1999a: p581.

Although familiar with textbook advice or analytic 'rules' from previous research and from my teaching of research methods, it took some time to translate these pedagogic 'tools' into practice. A major concern stemmed from my (personal) commitment to producing work that might claim some level of practical relevance. Fortunately, a growing number of those from the 'academy' of CA have contributed volumes that show how thoughtful analysis can address real practical issues and offer solutions to practice problems (e.g. Drew and Heritage, 1992; Peräkylä, 1995; Silverman, 1997; Heath, 1986; Atkinson and Heritage, 1984; Maynard, 2003; Glenn et al., 2003; Sarangi and Roberts, 1999). Nevertheless, several months observing clinics, sitting in the chemotherapy suite,

chatting informally with research nurses, clinic staff, doctors, patients and their families had left an impression. The temptation to laminate these observations – people's concerns, jokes, and worries - on to my data analysis of the talk-in-interaction was high. Moreover, although most in the world of social science admit to the utility of a focus on the minutiae, such detailed analyses can be and often are misconstrued as being situated in the realm of 'ivory tower' research, especially when compared to the work of colleagues who are involved in unearthing the mysteries of breast cancer genes!

Although aware of the EM/CA call for phenomenon to dictate that which is reported it was difficult in the first instance to fulfil this promise. Indeed, within this broad context, the notion of 'unmotivated looking' (Psathas, 1995: p45) seemed alien, unrealistic and self-indulgent. There was a large temptation to begin analysis by bringing problems to the data, "... using categories derived from social science and / or common sense, such as 'culture', 'power' or 'gender'" (Silverman on Sacks, 1998: p59). With this in mind, early questions underwent substantial revision. Eventually, I proceeded inductively and gradually moved away from definite ideas of what I might look at based on problems grounded in the early literatures and not in any serious consideration of the data; including, for example, 'emotion' in the consultation, 'power asymmetry' and so on.

Later (much later in fact) it seemed clear that it was more self-indulgent (not to mention poor research practice) to come to the data with views of, for example, 'good' and 'bad' communication styles, stolen from my early reading and experiences in the 'field' (especially given the fact that I had chosen my topic and method to move away from such work). If I already knew what I might find, the research endeavour itself was unnecessary and utterly self-indulgent! This is not to say that my observations in the field did not 'touch' or augment the detailed analysis i.e. after the phenomenon had been mapped. Having a broader knowledge of the other 'organisational layers' meant that I could effectively and credibly situate the consultations in the broader hospital context.

Initially two or three tapes were transcribed in full and early listening and reading suggested segments of the meetings that had particular analytic relevance. I became interested in the 'roles' of doctors and patients. While useful for 'setting the scene' this did not afford an explication of how doctors and patients produce, manage or orient to cancer information.

After much sifting, sorting, finding phenomena and dismissing them, Sacks' call to "just let the materials fall as they may" and "look to see how it is that persons go about producing what they do produce" made sense (Sacks, 1992: Volume I, Part I, Fall 1964-Spring 1965, LC 1: p11). Indeed, some of the best work evolves from theoretical concerns or single analytic puzzles, and not necessarily out of 'social problems' as already conceived before the work of analysis commences; 'We sit down with a piece of data, make a bunch of observations, and see where they will go' (Sacks, 1992: Volume I, Part VI, Fall 1967, LC 5: p664).

Early analysis of how the consultations recurrently played out chimed with Paul ten Have's (1991) description of the medical consultation as a distinct genre, consisting of recurrent activity types or "phases". In the specialist cancer meetings, as in ten Have's primary care medical encounters, the consultations seem to have a typical order: 'opening', 'history taking', 'examination', 'diagnostic embellishment', 'treatment talk' and 'closing'. Peräkylä and Silverman's (1991) work on HIV counselling and the different communication formats of information / advice delivery (IDF) and interviewing (IVF) also applied to much of the work done in the cancer consultations, due in very large part to the institutionality of the events. This institutionality was ongoingly evoked and oriented to in and through patient and doctor task orientations.

Later observations led me to look in detail at a range of practices and other conversation analytic work (Beach, Maynard, Peräklyä, Heath, Silverman, Bergmann, Drew, and Stivers and Heritage to name a few) was central to my evolving analysis. These influences are made known in and through the data analysis.

2.5.2 *Timing of information*

> The [focus] group clearly identified one of the central paradoxes of health information: that when people most need it they are least able to deal with it. This paradox between need for and coping with information has many implications for the development of an information strategy and appropriate materials to support this.
>
> CHiQ Report Series 3, October 1998

The CRC project had afforded an insight into the broader organisation of patient care and patient efforts to obtain information about their illness. It was clear that the timing of information was complex. The need for information, independent decision-making and discussion about cancer, seemed to shift over time and vacillate back and forth.

Whilst this broader puzzle is not of direct concern to the analysis shown here, it is important in terms of how to situate the data fragments in patients' broader illness paths and their interactions with doctors (See *Diagram 1*; *Chapter One*). All of the consultations dealt with in this thesis are first (or second) time meetings with the radiotherapy or chemotherapy Consultants and, at this point, patients are at a relatively early part of their journey. Longitudinal studies have shown that 'lay' contributions can increase over time as they become more familiar with the setting and the doctor with whom they are engaged (Silverman, 1987). In line with this, patient turns in these 'first meetings' often consist of continuers and conventionalised response tokens to the information and advice provided. It would be easy to count turn types and then raise questions about the extent of patient participation, why the 'lions share' of talk is doctor talk, and more particularly to question the 'quality' or 'appropriateness' of the doctor's skills and so forth. However, sequential analysis can help to show how even subtle actions, such as silences, can provide space for or elicit patient talk (see *'Choosing Methods: Costs and Benefits', Section 2.6.1*). And, as stated, the place of the patient pathway can influence the level of patient talk. It is here where longitudinal data are most informative.

2.6 The research topic (at last)

Eventually, with all of these issues in mind, my PhD came to be concerned with the following:

> How is it that the outpatient oncology treatment consultation "comes off" and how do participants offer and receive 'information' about cancer?

This large question fuelled early analysis and, following repeated listening and reading, the study became concerned with particular sets of practices that occur at separate moments in the consultation trajectory. Solo analysis was augmented by group analysis (or 'analytic jam sessions' Schegloff, 1999a: p578) and the two approaches aided my uncovering of initially 'unseen' activities and later my articulation of them. Even with a small data set of 27 tapes there was an "indefinitely expandable set of noticings" (Schegloff, 1999a) on which I could have reported but, for what I hope are obvious reasons, many have been disattended to in favour of a detailed focus on others. To recap, these include an examination of the work that goes into:

(1) The establishment of what each participant knows of the other during early history taking, including the journey to the here and now of the consultation.
(2) The naming / topicalisation of cancer during later history taking moments and clarification that patients' own their cancer diagnosis.
(3) The delivery of further diagnostic news once cancer is established as the diagnosis. The provision of evidence that prepares the way for talk about treatment, radiotherapy or chemotherapy.
(4) The negotiated meaning and delivery and receipt of different types of news (good and bad) and their relation to an (accomplished) omni-relevant context of uncertainty and positivity.

These activities were not randomly selected or preordained, but were eventually chosen as central, interrelated and recurrent activities along the cancer consultation, with one

paving the way for the other. In this sense, the unfolding trajectory of the consultation provided the guide for what should be interrogated. The usefulness of such an explication of some of these key practices is addressed throughout the thesis and then again in the Discussion (*Chapters Seven* and *Eight*).

2.6.1 Choosing topic; choosing method: The costs and the benefits

> ...Virtually any practice which one adopts for its virtues can be complained of for its (sometimes alleged, often real) shortcomings.
>
> Schegloff ,1999a: p565

All studies have routine methodological limitations, such as sample size and composition and the associated limits on the claims to generalisability that can be made in the light of such factors. Some of the limitations of my particular study were dealt with in *Chapter One* and I revisit some problems in the Discussion. Here I want to address a few specific criticisms that have been levelled at conversation analytic work. In so doing, I provide some counter arguments.

To be sure, in choosing one route, other just as feasible and reaonsable routes were ruled out. So in choosing *a way*, certain critiques become all the more apparent. As well as criticisms from external sources, those engaged in the business of qualitative enquiry have become ever more self-conscious and reflective about their own shortcomings. This general tendency towards a more self-critical line on the representation of data and claims that can be made of those data, can become unhelpful when taken to their extreme. There is, as Gubrium and Holstein (1997) argue, a danger of empirical analysis being threatened or overwhelmed by 'procedural self-consciousness'. A more pragmatic line of being aware of and attempting to confine the limitations is a more realistic approach. Striving for perfection can only promise "methodological paralysis" (Melia, 1997). That said, in the following pages, some of the potential problems with this and other studies influenced by conversation analytic principles are outlined and a justificatory word is said on each.

2.6.1.1 CA's 'narrow' focus

One-off recordings provide a view of a fraction of the entire cancer journey. The importance of the timing of recordings in terms of the nature of the material discussed in any one consultation, the rapport between interactants and other such matters cannot be ignored. Recording single encounters carries a risk of oversimplifying and perhaps obsfucating 'longer-term temporal processes'[13]. Peräkylä notes:

> Although tape-recorded data have intrinsic strength in terms of accuracy and public access, special attention needs to be paid to the inclusiveness of such data. Video or audio recordings of specific events (such as telephone conversations, medical consultations or public meetings) may entail a loss of some aspects of social interaction, including (1) medium- and long-span temporal processes, (2) ambulatory events, (3) and the impact of texts and other 'non-conversational' modalities of action.
>
> Peräkylä, 1997a: pp203-4.

In the same paper, Peräkylä (1997a) suggests that one way of overcoming this limitation is to ensure knowledge of the other 'layers' of the organisation in which the research is taking place e.g. observing interactional events, taking field notes and reading relevant documents produced for and used by 'organisations'. It was with this in mind, combined with a genuine interest to see how cancer clinics work more broadly, that I observed clinic consultations, sat in the clinic waiting rooms and attended some of the multidisciplinary meetings in which 'cases' were discussed. While attending to participants' orientations was the central task of the analysis, I brought to that analysis a certain level of 'cultural competence' or knowledge of the broader organisational contexts in which the consultations played out.

It should be clear that CA permits the study of language as central to people's understanding of what they do themselves and the actions of others. Given that '...the

[13] One remedy to this limitation is to adopt a longitudinal study design. Unfortunately, as stated, my MRC funded longitudinal data were not ready in time for this thesis.

social world is a pervasively conversational one', CA and audio-taped data provide a valuable aid to studying the social world (Heritage 1984: p239). Even one-off recordings allow detailed descriptions of what people do and how. They provide the possibility of 'repeated and detailed analyses of the events of interaction' that can 'extend the range and precision of observations' (Heritage 1984: p238). In addition, as Sacks spelt out some time ago, and as mentioned in the Introduction (*Chapter One*), the provision of detailed transcripts in the final work enables others to contest or concur with the claims made.

It is true that a focus on talk alone ignores the importance of gestural work. To return to my interview data, patient narratives uncovered a constant search for embedded meanings in gestural communications. For example, one patient reported that she guessed her cancer diagnosis by observing a "grim" expression on the surgeon's face following surgery [ID:1; 50-year-old female breast cancer patient], another noted that she could "tell from his face what had happened" [ID:4; 46-year-old breast cancer patient]. Regardless of the status of these remarks, detailed studies using video data have demonstrated the importance of capturing the gestural components of interaction. Heath's (1984a) detailed examination of 'talk and recipiency' led him to look at 'sustaining participation in interaction', and this work clearly shows how silences must not be viewed as a *break* in interaction but as "action slots", where non-verbal cues – such as postural shifts and shifts in gaze - might offer or elicit a "co-participants' recipiency to the ongoing social interaction". Similarly, the "interdependence of talk and bodily conduct" was demonstrated by Heath (2002) in a study that sought to show how patients in general practice consultations demonstrate symptoms and suffering in and through their gestural and other bodily conduct. With this in mind, the limitations of using audio data are palpable but in the case of this thesis were, nonetheless, inescapable.

> If the upshot is methodological paralysis it may be better to take a more... pragmatic approach to methods and do what is plausible.
>
> Melia, 1997: p34.

The practical constraints imposed by time, resources and ethics precluded video recording the outpatient oncology consultations. Analysis was performed with these limitations in mind.

2.6.1.2 Neutrality and CA

Because of a commitment to attend to participants' orientations and not to those presumed by the analyst prior to detailed analysis, CA has been accused of ignoring broader and important socio-cultural factors and manifestations of those in–interaction. 'Power' is a classic example of a topic or social practice that is thought to be ignored in favour of an assumed equality in all interaction. In a debate, played out fully in *Discourse and Society*, Billig (1999a,b) criticises CA for its emphasis on 'co-construction', and 'equal' participation of participants. He also states that the non-ideological or uncritical stance of CA precludes any serious consideration of such things as inequality and that sociological neutrality could productively be abandoned in favour of a critical gaze or awareness. Schegloff (1999b) responds fully to this criticism and states that in a discussion of turn-taking they do not "*presume* an equalitarian society, it *allows* for one...". He continues:

> ...[T]hose who take conversation or other talk-in-interaction to be basically an arena of oppression should undertake to show that; the available tools of analysis do not preclude that showing.
>
> Schegloff, 1999b: p564.

The problems raised by Billig (1999a,b), in my view at least, seem to reflect not necessarily CA's refusal to consider anything but a 'consensualist' approach, but rather a continuing problem of semantics and language among some of those working within and outside of the CA canon. Billig's critical standpoint raises serious questions about the aims of research such as that presented here. Indeed, having some knowledge of broader questions of the day and the institutional organisation more broadly is significant. Ethnographic material can help to define broader contexts and while these details should not inhere in the analysis of the discourse units selected (Schegloff, 1999b), they can

nonetheless be informative without blurring the view of what is going on or jeopardising the "autonomy of the data" (Wetherell et al., 2001: p386). In the end, an orientation to the "autonomy of data" is based on a particular theory of social action and not some ideological "naïveté" or neutrality.

> There is no ideological veil in CA that precludes analysts finding in a strip of interaction what is going on there, and in a collection of strips of interaction a recurrent practice deployed by participants in interaction.
>
> Schegloff, 1999b: p567.

Indeed more recent studies influenced by the principles and methods of CA have investigated such things as 'sexual refusal' (Kitzinger and Frith, 1999) and 'interethnic communication' (Cook-Gumperz and Gumperz, 2002). So, 'culture' and 'social relations' as embedded in social practices are open to investigation.

2.6.1.3 Vernacular vs. CA jargon

Billig has also suggested that while CAists claim to attend to particpants' orientations they in fact fail to do so by 'imposing' their own analytic terms; terms which the particpants themselves do not deploy. In response to this, I need say little as Schegloff neatly casts aside the relevance of this charge.

> ... [T]hey [participants] do not talk *of* adjacency pairs, they (mostly) talk *in* them; they do not talk *of* preference structures, they construct their talk by reference *to* them...; they do not talk *of* recipient design, they *exhibit* it in their selection of words, reference forms, topics, etc....
>
> 1999b: p570.

Moreover, CA is not alone in its use of a disciplinary jargon. Description relies on language and the language of CA is based in established disciplines like that of linguistics. As Lepper (2000) points out, CA is not calculatingly impenetrable but is grounded in that which has gone before and in this sense is no different to any other social-scientific approach to understanding social life. Furthermore, it is not just academics who play language games or own and ongoingly produce a distinct lexicon. Teenagers, sportspersons and just about any social category or group with distinct sets of practices can produce an equally impenetrable lexicon when viewed by 'others'. A little patience (and curiosity) can bring the associated meaning(s) sharply into focus.

On the fragments reproduced in this thesis I provide some ethnographic particulars[14] - Dr: (doctor), and Pt: (patient). By labelling the interactants as doctor and patient I am aware that I risk "insisting into relevance these categories and the bodies of common-sense knoweldge organized by reference to them" (Schegloff, 1999b: p565). However, given the interactional business at hand, the discourse or category terms of doctor and of patient make sense. Further, the "category shadow" problem is a minimal one: readers will "find what *they* find, and not what the author has stacked the deck in favour of finding by analytically tendentious labelling of speakers" (Schegloff, 1999b: p566).

[14] *Appendix V* provides a table for each chapter that details the cases used in each chapter and the hospital site from which each case was drawn.

2.7 A summary

In this chapter, I have described some of the relationships between study design, methodology and reviewing of the literature. In so doing, I hope to have shown how the formation and execution of the final study was not without its problems, both practically and methodologically. The final research project, questions and approaches were born from an entirely separate project and literature that became quite distant from the final research process and product. The ways and means through which I originally sought to define a research problem and collect data challenged my understandings of the domain of interest and the methodologies required to comment on a relevant and interesting component of a larger whole.

Finally, we now can move away from describing what I have done to show through the data what doctors and patients can do.

PART TWO - HISTORY TAKING

3.1 Introduction

PART TWO examines one aspect of the consultation, that of history taking[1]. History taking serves a major function in ensuring that patient details are collected and complete. In consultations with patients who may be described as 'expert' or 'experienced' patients (relative to patients presenting with acute episodes in general practice) and who have already received a diagnosis, history taking may serve quite a different purpose when compared with, for example, primary care meetings in which practitioners are attempting to ascertain a diagnosis. The basic question that initially interested me and led me to focus on history taking in Part Two was, 'how do two people who have never met before get acquainted?' and 'how do they raise the potentially delicate issue of cancer?'.

PART TWO is separated into two chapters and draws on fragments excerpted from the consultations once participants have achieved co-presence and greetings are complete. In the first chapter (*Chapter Three*), I demonstrate how the business of history taking is initiated. Once history taking is set up as the focal activity, we can see how doctors attempt to construct themselves into the patient's journey, which is understood and oriented to as transcending the snapshot meeting in which participants are engaged. Through particular question formats – open questions, "tell me how you first noticed this" and declarative or candidate tag questions, "you presented with bleeding, is that right", doctors contiguously show what they know (from the notes and meetings with other doctors) and request confirmation or invite patients to fill in the detail, in their own words.

There is a cautious epistemics to this history taking work. That is, doctors do not solely rely on the validity of the notes held but generally rather seek confirmation from those who know about the journey-to-diagnosis first hand – that is, the patients.

[1] Unlike H1, the history taking at H2 did not collect details such as living arrangements, previous illness and so on. It simply dealt with their journey to diagnosis; whom the patient had seen and what had been happening to them, which is the analytic focus at both hospitals.

This work suggests an orientation to who 'owns' that which is being discussed and this invokes Sacks' (1992) comment some time ago about how the right to report on this or that is a 'carefully regulated thing'[2].

I became particularly interested in the moments when doctors invite patients to tell them 'how this all started', ' how they presented' or 'noticed the symptoms'. This seemed to act as a *way in* to 'getting acquainted' or establishing a common ground. The questions are also particularly interesting because their position occurs at a moment in the consultation which is conventionally viewed as (only) consisting of rapid fire questions and answers. In contrast, the questions examined give patients licence to take the floor and to do so over a number of turns.

It became obvious that to analyse the doctor initiated questions in isolation from patient responses would limit what I could say about the work being done during the early history taking moments. Indeed, I would fall into the "doctor-centred" analysis of the medical interview that much of the research on doctor-patient interaction is guilty of. I wanted to contribute to, "a recent and growing adjustment [in research] to bring into clearer focus... the way that [patients] impact on the interaction between patient and doctor" (Drew, 2001: p262). Thus, I moved to see how patient answers get produced. As Sacks (1992: Volume II, Part 1, Fall 1968, LC2) showed us, what is relevant or "storyable" may differ from one conversation to another and the procedures used for producing and for listening to a story can vary in interesting ways. What gets 'worked up' for any single occasion is in no way accidental but represents a concerted effort.

The work of Stivers and Heritage (2001) on extended responses in history taking in one primary care meeting is particularly useful for honing the focus on patient responses to the questions deployed. Their case study investigates patient expansions during history taking – when more information than that requested is offered. Whilst useful, Stivers and Heritage (2001) report on just one patient and her consultation in a primary care setting with a mid-level health care provider. In this thesis I consider

[2] Due to space constraints, this will not form an explicit focus in the analysis, I merely wanted to introduce this as one possible analytic focus which came into view and then was relegated in favour of another.

secondary care meetings with patients who are seriously ill, where history taking (demonstrably) involves establishing the patient's place on a trajectory that has already been set in motion.

In *Chapter Four*, I show that once it has been established when and how patient journeys began, doctors attempt to solicit what patients know about their diagnosis. This involves them asking patients to tell "What Mr X said after the operation" or "What has been told to you so far?". Maynard's (1991; 1992) work on the Perspective Display Series (PDS) is critical in understanding the ways in which patient perspectives / knowledges / understandings of what has happened are solicited.

In *Chapter Four* it becomes clear that history taking in outpatient oncology does not play out in a way that consistently invokes the obvious asymmetries suggested in some of the classic literature on doctor-patient communication (e.g. Byrne and Long, 1976; Tuckett et al., 1985; Balint, 1957; Mishler, 1984). Rather, in line with the work of Maynard (1992), patient interventions can be critical to the ongoing interaction. In addition, in line with the work of Stivers and Heritage (2001), despite the ongoing *constraints* of the Q-A format, patients can and do skilfully weave "life world" material into their answers – invited and uninvited. We will see that "patients' contributions – volunteered or elicited – play a central part..." in terms of how patient histories are established" (Sarangi, 2001).

Both chapters are discussed at the end of *Chapter Four*. Each suggests that there is a need for caution in speaking too generally about history taking as a generic form. Whilst questions are asked and answers proffered and the organisation of these two activities is distributed in doctors' favour, so that they get to initialise the questions (Robinson, 2001), it is empirically evident that a specialist meeting takes place between specialist members - physicians and patients - and this can be consequential for the types of actions performed and the level of patient input.

3.

Establishing the patient journey to the here and now

3.2 Organisation of this chapter

This chapter is divided into three broad sections. In *Section 3.3,* I consider how doctors and patients make the first move to business following the opening greeting sequence (not discussed in this thesis). Next, in *Section 3.4* the question types deployed to access information about the patient journeys to the here and now of the consultation are considered. Two key question types are used to achieve this. I have simply called these open and closed. In *Section 3.4.1*, examples of the closed interrogatives are listed and three exemplars are examined in detail, together with the answers produced in relation to them. Next, in *Section 3.4.2*, open interrogatives are considered. This is followed by a more detailed examination of three questions and the answers produced in relation to them. Finally, in *Section 3.5* the observations made about the question types and the implications for understanding the activity of history taking in specialist treatment meetings in oncology are discussed.

3.3 History Taking: A word on the first move to business

> Communicating such important information when there is no pre-existing relationship clearly presents difficulties to both doctor and patient.
>
> Walker et al., 1996: p9.

Traditionally, as noted in *Chapter One*, the majority of studies that have examined communication (however defined and studied) in the oncology setting have focused on the 'bad news interview'. Indeed, the quote from the King's Fund above refers to such occasions, when doctors have the 'difficult' task of relaying important information, notably the initial diagnosis. In the following two chapters we shall see that doctors responsible for adjuvant therapy (radio- or chemo-) are also in a position whereby diagnostic details, which may or may not have been shared previously or shared but not retained by the patient, have to be (re)-stated. The King's Fund

comment above can equally apply to the moments reviewed in this thesis, where the doctors recorded have (on the whole) never met the patients or have only met once briefly and, as such, have no "pre-existing relationship". Consequentially, together they backtrack or rewind to recap on what has been happening (*Chapter Three*) and what the patient knows (*Chapter Four*).

Before examining the questions proffered by doctors and the responses provided by patients, let us first see how two 'strangers' move to the business of the history taking. As a *way-in,* doctors introduce the topic of a patient's case and do so by stating that they know something about them from another source, often the surgeon (Mr X). This first step forecasts doctors' interest in patient journeys to the *here and now* of the treatment consultation.

In addition, the way in which doctors tender the information they hold about the patient invokes a certain collegiality through reference to other doctors and sources of evidence (discussed in greater detail in *Chapter Five*). For example, in the early stages of the consultations dealt with in this chapter doctors tend to orient towards their case notes (when they have them[3]) and they lead themselves and patients through what has happened in previous moments along the patient pathway.

Let us consider *Extracts 3.1, 3.2, 3.3* and *3.4.*

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[3] In this example, the doctor mentions that he does not have the patient's notes. He orients to other structural resources (meeting other doctors) and he states that he still knows what has been happening.

Case A, H1

Dr: RIght (2.0) if I can .hhh first of all go through (.) what's been happening (.) to you, then have a look at you (.) and then take things from (.) THere. °alright?°

Pt: °yeah°

Dr: first of all I must aPOLogise, I haven't actually got your (.) notes: (.) in front of me <today> I don't know where they are (.) last Monday though we discussed the case (.) with Mr X=

Pt: =°yeah°=

Dr: =so I'm (.) know what's (.) BEEN happening=

Pt: =yeah, yeah=

Dr: =but I need to just recap a little bit over, sort of dates etc. alright. (.) also when I'm talking to you, if there's anything (.) I say that you're not sure of, please don't hesitate to interrupt

Extract 3.1 (Case 1).

01. Dr: heard a <little bit> about ↓you=
02. Pt: =um=
03. Dr: =from Mr X's t↓eam (.) what I'd like us to do is <sort of> recap over what has been
04. happening (.) have a look at you and then explain where we go from here=
05. Pt: =°yeah°
06. Dr: al↑right

Extract 3.2 (Case 2).

01. Dr: right <Mr X> if I can just (.) recap a little bit over (.) things (.)
02. obviously Mr Y has written to me=
03. Pt: =yes:=
04. Dr: =and (.) so I know something about you=
05. Pt: =yes=

Extract 3.3 (Case 3).

01. Dr: hello Mr X (0.5) I'm Doctor Y (2.5) you met Mr Z my registr↑rar
02. when you came to OUr clinic (.) about ((disturbance of machine))
03. (°sorry about that°)
04. Pt: ([ )
05. 3rd p: [((cough))
06. Dr: yeph, yeph, I was-I was-I WAS THERE and Doctor-I-I-Doctor Y
07. actually saw you and er:=
08. Pt: =yeph=

Extract 3.4 (Case 4).

01. Dr: um (2.0) ° I (haven't) introduced myself (.) I'm Dr X°
02. Pt: yeah
03. (1.0)
04. Dr: you've come to us via Mr Y, your ( ) surgeon
05. Pt: yeph

I only want to make some broad points about these extracts. The first of these is that in setting the agenda, structural resources (Bergmann, 1992) are hearably invoked in

the *here-and-now* of the consultations. The key features of these agenda setting moments are that doctors:

1. Orient to the patient pathway stemming beyond that of the *here-and-now* of the consultation (i.e. other meetings and experiences along the illness path) (e.g. *Extract 3.1, L3; Extract 3.2, L2; Extract 3.3; L1, 6*).
2. Orient to other health professionals (often the surgeon) who have treated the patient (e.g. *Extract 3.3, L1*).
3. Orient to their notes or their need to recap/refresh/gain/check knowledge (e.g. *Extract 3.1, 3-4*; *Extract 3.2, L1*).
4. Produce formulations that orient to having some knowledge, thus remaining morally accountable as a member of the category type *expert-doctor*, while also portraying the limits to that knowledge (e.g. *Extract 3.1, L1*; *Extract 3.2, L2*; *Extract 3.3, L6*).
5. Imply a requirement for the doctor to learn more from the patient about their trajectory thus far.
6. Imply a need for the patient to be aligned to the activity of sharing their knowledge of events to date.

These features inhere in the work done throughout 'history taking'. This work does not, however, form the primary focus of analysis, but provides an important insight into the work done in the move to (and during) history taking. It is worth noting at this early juncture that during these early moments, mention of cancer is generally held off. Rather than mentioning the topic of cancer immediately, doctors (and patients) generally 'dance around' the cancer diagnosis[4]. Indeed, we take two chapters to discuss just how this is accomplished.

Having briefly established how doctors make their first move to the business of history taking, let us view how they proceed to establish some 'common ground', by getting acquainted with how patients presented initially and came to be diagnosed with a cancer.

[4] See Beach et al. (2005) for a discussion of cancer as a 'fearful' issue, marked as delicate during early consultation moments or Lutfey and Maynard (1998) for a discussion of the avoidance of the terms death or dying by doctors and terminally ill patients.

3.4 Question types: 'How did the patient get to the here and now?'

In this, the core section of this chapter, I introduce two broad and recurring question types that occur at the beginning of history taking. I have chosen to categorise or gloss the questions as performing an action of establishing a common ground by virtue of the fact that they are aimed at establishing a mutual knowledge of how patients came to be diagnosed with cancer. In turn, the information gleaned via the questions functions to provide a basis from which to conduct further history taking (and to talk directly about cancer). More locally, the questions are designed to solicit confirmation of information held about patient journeys to diagnosis or augment that which is already understood by doctors. In terms of their turn design and lexical composition these questions are variously formed, but two broad categorisations can be suggested. These are shown below (without transcription conventions).

Closed interrogatives: e.g. "you presented with a lump initially to Dr X, is that right".

Open interrogatives: e.g. "tell me how this all started"[5].

The closed questions shown are labelled as such because they project a yes / no-type answer or a confirmation / disconfirmation. By contrast, the open questions invite patients to provide information *'in their own words'* about how they first noticed a symptom, or how "this all started".

Some time ago, in a discussion of the negotiation of discourse in the medical consultation with mid-level providers, Drass (1982) outlined a number of question and response forms. Three of his six categories can be collapsed and cross-matched to the two suggested in this chapter i.e. closed and open. These are as follows:

[5] Later, in the Discussion (Chapter Eight, p281), I discuss the limits of labelling these activities rather simply (and opaquely) as 'open' and 'closed', but for now I stay with this classification.

Closed

Tag-question – an interrogative consisting of two parts: a statement describing the [doctor's] understanding of some aspect of the patient's history with his / her problem and an interrogative requesting the patient to confirm or disconfirm this understanding.

Doc: And, uh, were they, they weren't' any different from the other ones – right?

Pat: No.

Request for confirmation: – a declarative which implicitly requests the patient to confirm or disconfirm information about his / her medical problem.

Doc: Ok. All of a sudden it hits you.

Pat: Yes.

Open

Information request: an interrogative which calls upon the patient to provide information, in his / her own words, about some issue raised by the mid-level provider.

Doc: Ok. What's getting worse then?

Pat: Uh, oh, the only thing I was concerned with was... ((Continues narrative telling)).

[Source: Drass, 1982]

According to Drass (1982) both classes of questions solicit patient answers and these may be categorised in one of three ways:

1) Reply – does not go beyond the information requested.
2) Expansion: reply + correction / reformulation.
3) Expansion: reply + material not requested by the question.

In the first meeting fragments considered for *Chapter Three*, 6 of the 8 closed questions are responded to in minimal terms (1 or 2 above). Nine of the ten open questions are met with longer patient answers (3 above). During the analysis we will consider a range of these.[6].

In terms of the position of the question turns, they all appear at the early stage of history taking.

[6] A cautionary note is required about the categorisations so far discussed. As with any taxonomy, the complexity or murkiness of the distinctions between ways of questioning or answering as they occur in interaction may become promiscuously glossed. Indeed, such categorisations can obfuscate rather than elucidate complex sets of practices. Therefore, these question and response categorisations are to be viewed only as a *way in* or a 'key' to accessing the work that doctor questions and patient answers *do*.

As well as considering the question types, I discuss the information provided in the patient answers. For example, patients may produce answers over a series of turns and may weave material into their answers, which can be categorised as 'life world' information (Stivers and Heritage, 2001). Moreover, patients may exploit the 'open question' format to produce stories of misdiagnosis or of waiting to enter the 'sick role'. So too, patients may craft answers in such a way as to produce themselves as "morally adequate" or of acting reasonably when faced with bodily change by, for example, seeking out expert medical advice rapidly.

3.4.1 Closed interrogatives: "You presented with bleeding, is that right?"

Eight examples of closed interrogatives are listed in *Table 1*. I realise listing them in this way is somewhat unsatisfactory because they are abstracted from their natural sequential environment. Nevertheless, it clarifies what I call here 'closed questions'. I have also listed the type of response the questions solicit. In 6 of the 8 cases the answers can be categorised as replies, which attend directly to the project of the question, without expansion (1) or with minimal expansions (2). The latter still attend to the project of the question but also work to offer correction. Two of the 8 cases result in storied expansions, where patients context their answers in a broader story of their journey to diagnosis (3).

Table 1: Eight examples of closed interrogative

Extract	*Case*	*Site*	*Question*	*Answer*	*Third position*
3.1	5	H1	o↑kay (.) NOW looking back ↑through your notes (.) you presented with some bleeding ↑didn't ↓you?[7]	Reply	+ Next questions
3.2	6	H1	°right° ((rustle of papers)) now you presented (.) to Mr C (3.0) ((rustle of papers)) in: January <is that right>?	Reply + correction	+ Next questions
3.3	2	H1	now you presented with (.) pain <is that right>?	Reply + correction	+ Next questions
	7	H1	.hhh and you presented ↑to (.) ↑Mr (.) ↓X <is ↓that ↑right> o:r <YOU [↑WENT TO] MR Y> ↓THEN Mr ↓Z did the opera↓tion?	Reply	+ Next questions
	8	H1	↑NOW this particular <episode> all started when you were found to be an↑emic is that ↓right?	Reply	+ Next questions
	1	H1	r:↑ight now this all started by you noticing a ↑lump in your breast is that r↓ight?	Reply	+ Next questions
	9[8]	H1	this all started with (.) w- an↑gina is ↑that ↓right (.) [(and slightly an↓aemic)]?	Reply + storied expansion	
3.4	10[9]	H1	Now you pre↑sented (.) to Mr (name)'s team with (.) some ↓bleeding <is that ↑right>?	Reply + storied expansion	

I want to discuss the first three of these closed question examples. Once the questions have been examined, patient answers will be considered. I will then examine *Extract 3.4 (Case 10)*, in which the patient produces an expanded answer.

[7] There are many more issues that could be discussed, which are beyond the scope of this thesis for practical reasons of space. For example, this particular question has a query tag that is negatively formulated, unlike the other questions. Thus, it is not simply a case of whether a question is 'closed' or 'open'; other features of the turn design may be consequential for the next speaker. Thanks to P. Drew and C. Heath for this comment.

[8] This extended response may in part be 'explained' by the utterance that preceded the doctor's question. That is, the doctor stated, "now I know you had an operation one month ago". This informs the patient that he knows something and implies that he might like to know more. This is the only question that is not the first in a series.

[9] We go on to review this answer, but it is worth noting at this point that this extended response involves the patient informing the doctor of an initial misdiagnosis. He was told by his GP that he had piles, which subsequently turned out to be bowel cancer. Later in this chapter we will see that expanded answers in response to the open questions often involve patients telling stories of misdiagnoses or of long waits before diagnoses were reached.

3.4.1.1 *The questions*

Extract 3.1 (Case 5).

01 Dr: o↑kay (.) NOW looking back ↑through your notes (.)
02 you presented with some bleeding ↑didn't ↓you

Extract 3.2. (Case 6).

01 Dr: °right° ((rustle of papers)) now you presented (.) to Mr X
02 (3.0) ((rustle of papers)) in: January <is that right>?

Extract 3.3 (Case 2).

01 Dr: now you presented with (.) pain <is that right>?

Extracts 3.1, 3.2 and *3.3* show question turns that are composed of separate parts or units. Each has a turn initial 'right' or 'now', which signals that the doctor is about to move into a new activity (Mehan, 1981). Following the turn initial, the doctor presents the candidate first step on the 'journey' to diagnosis ("bleeding", *Extract 3.1*; "pain", *Extract 3.3*), to whom they presented ("Mr X", *Extract 3.2*) and when ("January", *Extract 3.2*). All three have interrogative tags, and these explicitly request patient confirmation or disconfirmation of the doctor's understanding ("didn't you", *Extract 3.1*; "is that right", *Extracts 3.2* and *3.3*).

Let us consider for a moment what key actions are being performed through such questions and why doctors might construct them in this way. Most obviously the doctor is performing an action of requesting confirmation or disconfirmation. Beyond this, the turn construction invokes a particular kind of relationship between the doctor and the information contained in all three questions. One clue to the kind of relationship invoked resides in *Extract 3.1*, "now looking back through your notes"[10]. All *Extracts*, either implicitly or explicitly (as with *Extract 3.1.*) reinforce that the information reported is gleaned from second hand sources, such as other people or

[10] This should act as a warning signal. If the doctor is attending to the notes then any silences in the talk need to be analysed cautiously, with this in mind. The important role of nonverbal behaviour in these sorts of meetings cannot be assessed because of the limitations of the data set. And yet, Heath (1984b) has shown us that verbal and nonverbal behaviour may be coordinated by a patient to illustrate a story and to get her doctor "to not only hear what's being said but to see the illustrative or iconic movements", while, for example, a somewhat inattentive doctor reads the patient's notes (p324)

notes, and that the information being proposed and re-characterised is drawn from another temporal moment, beyond the here and now of the consultation: talk is 'dialogical' (see Allistone, 2002). Earlier in this Chapter (*Section 3.3*) we saw how, during the first move-to-business, doctors implicitly or explicitly informed patients that although they know something about them, they are working from second or even third hand evidence of the patient journey.

Let us look again at the doctor's first turn in *Extract 3.1.*

01. Dr: o↑kay (.) NOW looking back ↑through your notes (.)
02. you presented with some bleeding ↑didn't ↓you

Following the doctor's turn initial, "o↑kay (.)", the second part of the doctor's turn, "NOW looking back ↑through your notes (.)" tells the patient that as the doctor he has access to some information via the case notes, and his adequacy as a member of the category type *expert-doctor* is hearably upheld. That is, part of being a doctor is having (privileged) access to patient notes[11]. The doctor's turn also tells the patient that the information he holds is second hand and in so doing he sets up a contrastive role for the patient as *the-subject-actor-with-the-first-hand-version-of-events.* That is, it is the patient who has been diagnosed, had the operation and so forth and hence has first-hand experience of the story so far. The doctor's third part of his turn, "you presented with some bleeding...", provides a formulation or a 'gist statement' about how the patient came to visit the GP. This is followed by the query intoned tag "↑didn't ↓you", which again orients to the patient as someone who is in a position to confirm or disconfirm the proposed history.

One challenge faced by clinicians in these situations is that they are working from clinic records that contain second hand reports of how patients began their cancer journey. The information is in no way derived or grounded in the clinic in which the participants are currently meeting[12]. When viewed in this way, we can begin to see

[11] Here we are again reminded of the limitations of a sole reliance on audio-data. Speculatively, the construction of these question turns may have important links to the gestural engagement of the participants. That is, they may be about restoring eye contact after a spell of the doctor reading patient notes. The question construction may then be less to do with the future course of interaction and more to do with accounting for the past. The questions may work to say, 'I haven't forgotten you're there, even though I've been spending time reading these notes'.

[12] Further, as an aside, having spent months observing in clinic, the notes are often found to be incomplete. When I spoke to health care professionals they spoke frequently of the importance of

that there may be a certain epistemic caution in presenting[13] a patient's history in this way. The caution may be related not only to the potential incompleteness of information held, but to two further issues: first, the right to report on an event or experience is 'a carefully regulated thing' (Sacks, 1992) and, second, in highlighting the second hand nature of the information held, the doctor makes relevant (and with the turn construction sequentially obligatory) patient participation.

3.4.1.2 The responses

Let us now consider the responses that such an approach to question asking can solicit. As Drass (1982) described some years ago, these closed or 'tag-questions' generally project a simple yes / no / confirmation / disconfirmation response. This means that the parameters of what may be counted as a sequentially relevant next are tightly set. Let us consider *Extract 3.1,* preceded by a similar move-to-business to those reproduced in *Extracts 3.1-3.4* (in *Section 3.3).*

Extract 3.1 (Case 5).[14]

01	Dr:	**o↑kay (.) NOW looking back ↑through your notes (.) you**
02		**presented with some bleeding ↑didn't ↓you**
03		(1.0)
04	Pt:	dis↑charge [(.) yes: yes:]
05	Dr:	[d i s c h a r g e]
06	Pt:	yes that's right=
07	Dr:	=you then came to the clinic=
08	Pt:	=<that's right yes::>=
09	Dr:	=they exa↑mined you (.) [with a biop↑sy=
10	Pt:	[yes: °that is ↓correct°]
11	Dr:	=and then you had your operation on the (.) ↑twelfth↑of (.)
12		[↓June

---

having access to letters from other health care professionals, referral letters and, more generally, earlier pre-diagnostic details to assemble a full profile, before the business of chemotherapy and radiotherapy could be satisfactorily discussed.

[13] It is important to note my use of 'presenting' here – as opposed to 'taking'. That is, these closed interrogatives do sometimes give the impression of the history being presented to patients by doctors and not gathered, with the presentation performing a request for confirmation or otherwise.

[14] Cancer is not mentioned by the patient and towards the end of history taking the doctor asks for the patient's perspective on what has happened so far. We will view these "perspective invitations" (Maynard, 1992) in *Chapter Four.*

13 Pt: [that's right yes
14 Dr: .hhh first of all (.) how are you getting on after your
15 ↓operation.
16 (0.5)
17 Pt: I think I feel al↑right (.) um: there's nothing ↑wrong (.) at the
18 ↑moment (.) back's still a little bit tender (.) but it is getting
19 there
20 ((History taking continues))

Before considering the entire fragment, let us first consider the expanded Q-A sequence from lines 1-6. A tag-question is produced (1-2) and the patient provides a correction plus an agreement (4), following a (1.0) gap. The delay in response suggests a dispreferred action and indeed the patient proceeds to correct the doctor's proposal of "bleeding", using notably a technical lexical "discharge". Not only will patients correct doctors but also they may do so using non-lay terms. In third position, and in overlap, the doctor aligns with the patient's (re)-formulation by uttering "discharge". In other words, the doctor does not "sequentially delete" the patient's response but repeats it and thus 'deletes' his own prior understanding contained in his proposal 'bleeding'. Information about how the patient "presented" is treated as patient-owned and it is this version that interactionally prevails and this is re-confirmed by the patient, "yes that's right" (6).

To summarise this expanded Q-A sequence, the patient produces a correction to the doctor's closed interrogative, information is exchanged that is in contrast to that reported in the clinic records. Thus, even with such a minimal exchange, the requirement and utility of patient participation is affirmed. Following this first expanded Q-A sequence, the doctor proposes another step on the patient's journey to diagnosis, "=you then came to the clinic=" (7)[15]. The patient confirms the proposed pathway and the remainder of the doctor produced questions solicit confirmation. Patient input is, however, *limited* to the following turns, "=dis↑charge [(.) yes: yes:]" (4), "yes that's right=" (6), "<=that's right yes::>=" (8), "[yes: °that is ↓correct°]" (10), and "[that's right

[15] Note that this time this is a declarative and not a tag question. The first question with 'didn't you' is sufficient for the patient to hear the 'you then came to clinic' as a question. Sacks (1992) comments on this: "The chaining rule for questions is terribly criterial to the recognition of questions. Such that the first question in a sequence will regularly be independently recognisable as a question by, for example, a very pure grammatical form and / or a characteristic intonation, but that once a series of questions is started, then it may well be the case that [a next utterance by the questioner] can be heard as a question by virtue of occurring in a sequence of questions" (Volume 1, Part III, Spring 1966, LC14: p373).

yes" (13). In other words, the patient clearly orients to his role as confirming (or otherwise) doctor-produced information about his history with special reference to his journey to diagnosis. As Stivers and Heritage state the 'minimality of the patient's responses':

> ...exhibits his understanding of the 'checklist' status of the questions and his preparedness to comply with that understanding.
>
> Stivers and Heritage, 2001: p153.

This sequence resonates with the canonical view of medical meetings, especially the activity of history taking, as asymmetric, with limited opportunity for the patient perspective to come into view (e.g. Drass, 1982). As the initiator of the first action, the doctor has topical control and gets to speak again. Third turn options include producing an assessment, acknowledgement or a further question. Here, during history taking, the doctor asks further questions (in declarative form), to which the patient responds.

Another *statement-plus-query tag* or closed question is shown in *Extract 3.2*. This example illustrates another case of patient correction (as in *Extract 3.1*). The exchange is between a consultant and a woman with breast cancer.

Extract 3.2 (Case 6).

01	Dr	**°right° ((rustle of papers)) now, you presented (.) to Mr X**
02		**((rustle of papers)) (3.0) in: January <is that right>?**
03	Pt	ye:a↓h
04		(.)
05	Pt	no it was De↓cember
06	Dr	De↑cember=
07	Pt	=yeah
08	Dr	and that was with some dimpling=
09	Pt	=yes=
10	Dr	=on the skin
11		(4.5) ((rustling is not heard, but it might well be that the doctor is
12		perusing notes at this juncture))
13	Dr	and you had a BIOp↓sy (.) done at that p↓oint
14	Pt	er:: <yeah> it ↑was=
15	Dr	=with a needle=

16 Pt =y[eah
17 Dr [yeph
18 (6.0) ((again no audible rustling))[16]
19 Dr and then you had your operation with an immediate
20 reconstruction
21 (1.0)
22 Dr a↑b:out ((shuffling of papers))
23 Pt 29th of January
24 Dr °(okay)°

In *Extract 3.2*, the doctor produces a declarative with the query tag, "right now, you presented (.) to Mr X ((rustle of papers)) (3.0) in: January <is that right>?" (1-2). The doctor's turn involves the action of looking through the clinic notes, and features a (3.0) intra-turn pause while he (presumably) searches for the information he wishes to check with the patient. Again the turn initial "right now" is produced and is followed by the proposed journey of to whom the patient presented "Mr X" (the surgeon). The proposal also contains a candidate date, "January", gleaned from the patient's notes and again the query, "is that right".

In her response the patient does not attend to the first part of the doctor's proposal of the health care practitioner to whom she presented, but to the date referent, 'January'. She first provides agreement, "ye:a↓h" and following a small gap, initiates a repair on her prior turn, "no" which is through-produced with the correction, "it was De↓cember" (3-5). As with *Extract 3.1*, the doctor repeats the correction "December", which solicits further confirmation from the patient, "yeah". Repeats such as these have been found to occur in other settings. For example, Drew (1992) found that the presentation of evidence in courtroom settings occasioned such repeats.

[16] These silences are criterial to how these moments can and should be understood. If, as I think, the doctor is still glancing at the notes, then these are most likely to be intra-turn pauses, while the doctor identifies the next history fact to propose and get confirmed or otherwise (i.e. no warrant for the patient to speak). If, however, the doctor is gazing at the patient, for example, then these might well be inter-turn gaps in talk. Indeed, we can see that the doctor's turns at 10 and 17 are hearably possibly complete. However, it makes sense that the notes are being perused here and, as such, I address the silences in this way.

01. A: Uh now, Sergeant ((name)), was the print put on these before
02. the shotgun shell was fired or after?
03. W: Before it
04. A: Before?
05. W: Yes sir

[Source: Drew, 1992: p476].

Drew (1992) suggests that these 'objects' can work to underscore "a witness's prior answer" but more than this, it is underscored for the "benefit of the overhearing audience" (i.e. the jury). Legal comparisons, especially courtroom comparisons, do not work too well here. The 'guilt' of the patient is not at issue[17]; these meetings seem to be more about allies establishing the facts together. Here, in my corpus, such 'repeats' are more likely to be designed to check understanding and confirm the correction before (speculatively) doctors annotate the clinic notes with the new information or simply make a mental note of the shared information. The repeats also work to signal to patients that their corrections have been heard, understood and noted.

The rest of the fragment involves further questions and answers. The query tag is dropped from subsequent questions, which are also formed as declaratives (see Sacks, 1992) and they continue to solicit patient confirmation (or correction). Again, if we extract the patient turns from their sequential environment we can see that they are short and overall they provide confirmation / disconfirmation of the journey proposed, "ye:a↓h (.) no it was De↓cember" (3-5), "=yeah" (7), "=yes=" (9), "er:: <yeah> it ↑was=" (14), "=y[eah" (16) and, "29th of January" (23). The patient's actions are tightly tied to the doctor's topics and doctors' questions are designed to elicit short answers. The doctor sketches out the patient's journey towards diagnosis and the patient is sequentially obligated to offer agreement/confirmation or to offer an alternative sketch (which is a non-equivalent action).

[17] Having said that, later in this chapter (*Section 3.4.2.2*) we shall see that patients may exploit the opportunities provided by the open questions to provide answers that allow them to "come off" in a "morally adequate light" (Baruch, 1981). They appear to rebut a potential charge of not attending a doctor soon enough, for example. Although it is true of course that accounts may be produced when no accusation has been made, such as a rejection of an invitation, whereupon the rejecter will produce an account for the rejection (Drew, 1992).

Extract 3.3 demonstrates how patients might offer a more overt rejection of the proposed history. In terms of question type the "didn't you" is replaced with "is that right" (1). On this occasion we see 'expansion' in the patient's answer, which is still on-topic but works to correct the history proposed in greater detail than the previous examples.

Extract 3.3 (Case 2.)

01	Dr:	**now you presented with (.) pain <is that right>**
02	Pt:	yes:
03	Dr:	I'll just look back at your (1.0) ((sound of paper)) °notes°
04		you were admitted from (.) ↓casualty is that right=
05	Pt:	=nope=
06	Dr:	=no=
07	Pt:	=no, no, there was, it was through an appointment from m:y
08		um: GP=
09	Dr:	=right=
10	Pt:	I HAD <It started off I had diarr↓hea> (.) um: after that I HAd
11		(.) the small bowel (.) ↓blocked so I had the two things running
12		((sniff))
13		(3.5)

In *Extract 3.3*, the doctor again produces a formulation, "now you presented with (.) pain", contiguous with the tag "<is that right?>" (1), and the patient responds in the affirmative "yes:" (2). The doctor again refers to his reading of the notes, "I'll just look back at your (1.0) ((sound of paper)) °notes°...", which again works to tell the patient *I-know-something-but-I-am-working-with-second-hand-information*, and information that is generated from another temporal phase on 'your' pathway[18].

Extract 3.3 nicely demonstrates what can happen when the initial familiarisation of how the patient came to be in the health care system leads to not just correction, but elaboration of the information proposed (eventually after doctor's repeat (06) and

[18] Patient corrections to the information posed are often (though not always) less 'overt' than this example. More usually a "negative rejection marker" (Drew, 1992) will not preface patient turns. Rather, they are likely to produce an agreement followed by a different characterisation to that offered or characterisation followed by a post initial agreement 'yeah, yeah'. In other words, the competing description is constructed in more affiliative terms than that reproduced above.

continuer (09)). At line 4, the doctor produces another statement which formulates how the patient presented, contiguous with the query tag "is that right=" (4) to which the patient responds with a rejection "=nope=" (5). The doctor's repetition of the patient's correction "no" is similar to the repetition of the patient corrections in *Extract 3.2,* but on this occasion the repetition works to invite the patient to provide the correct information. The doctor's continuer (9) positions the patient as the information provider with the doctor consequentially positioned as recipient to the patient delivered elaboration (7-8, 10-12). The (3.5) inter-TCU gap in talk (13) represents a possible completion point of the patient's turn. Indeed, following this the doctor continues in the same closed question format in *Extract 3.3a.*

Extract 3.3a (Case 2).

01	Dr:	**and that resolved itself initially↑ [is] that right?**
02	Pt:	[no]
03	Dr:	=<no you had> a small bowel
04		(1.0)
05	Pt:	a(h)a ((click in throat)) small bowel [blockage
06	Dr:	[ENIMA, right=
07	Pt:	=yes um: and so the operation ↓on ↓the ↑co↑lon AND the small
08		bowel was done by Mr X at the ↓same ↓time
09	Dr:	↓right
10	Pt:	(°<as far as I'm aware>°) ((background noise))
11	Dr:	so (.) but when you first saw him he then did a (barium) enima? Is
12		that right?
13	Pt:	indeed=
14		(6.0)

This extract, when combined with *Extract 3.3,* provides a glimpse at how 'closed questioning' may not (as might be assumed) be a straightforward or economical way to proceed. Rather, such an approach can lead to a number of meanderings down incorrect or blind alleys. Sacks (1992) noted the following, when "the answerer leaves the questioner 'in control'":

> [This] can... be characterized as letting the questioner go off on as many wrong tracks as he pleases, where you can get a long, involved project that generates a series of questions, none of which turn out to have any use.
>
> Sacks, 1992: Volume 1, Part 1, Fall 1964-Spring 1965, LC 7: p56.

I am not suggesting that the patient does not 'cooperate' nor that the information generated turns out to have no 'use'. But, less extremely, the recurrent use of candidates or declaratives may not be as economical (time wise) as it may at first seem (when compared with fuller narrative accounts solicited via open question formats). For example, again we see that the doctor's proposal (01) is for the second time met with a rejection marker 'no'. The patient has fulfilled the adjacency requirement of providing an answer to the latter component of the doctor's turn, 'is that right', but the answer gives little clue of what 'is right'. At line 7, the patient does elaborate on the procedures undertaken prior to the consultation and his answer becomes interactionally complete on his utterance of a classic hedge 'as far as I am aware' (e.g. Stivers and Heritage, 2001: p156; Beach et al., 2005). The doctor's next turn (11) commences with the upshot particle 'so', however he switches tack with the contrastive 'but'. This may possibly be because the information so far shared is inadequate to produce the upshot of *what this all means*. The doctor again produces another proposal of a further step along the patient's journey, to which the patient responds with the affirmative "indeed".

There are many issues contained within this extract with which we could concern ourselves. Here, I want to mention just two features. First, any approach to communication has the potential to set up some double bind (Silverman, 1987). Indeed, how this is so in the spaces analysed in this thesis will be suggested on a few occasions. Here I suggest that although the 'closed interrogatives' may finely project (possibly constrain) the type of answer required and hence limit the introduction of 'superfluous material', so too it may result in too little information for the doctor and thus create a requirement to ask (many) more questions. Second, and contrastingly, medical meetings may be occasions where patient expansions occur, even when closed questions are posed. Moreover, patients might correct doctors and do so drawing on a medical frame. Whilst these moments show a degree of flexibility, it is still the case that the patients produce confirmations and disconfirmations, and although corrections and elaborations occur they are all closely on-topic. When compared to some of the fragments that we next consider, these patient answers to closed questions, including their expansions, must be classified as minimal. All of the Q-A series in *Extracts 3.1, 3.2* and *3.3* primarily work to (a) set straight the patient journey as presented by the doctor and (b) set the history taking in motion.

Finally, in *Extract 3.4*, I provide one more example of the doctor orienting to other structural resources (another doctor and his team) whilst a candidate pathway to diagnosis is offered; "now you pre↑sented (.) to Mr X's team with (.) some↓bleeding" contiguous with the query "<is that ↑right>" (1-2). On this occasion, however, the patient produces his response over a number of turns and provides material that is not projected or required by the question posed. Thus demonstrating the integral nature of patient input in terms of how consultations play out.

Extract 3.4 (Case 10).

01	Dr:	**now you pre↑sented (.) to Mr X's team with (.)**
02		**some↓bleeding <is that ↑right>**
03	Pt:	what
04	Dr:	you presented with some BLE↓eding. <some> (.) from your
05		back passage
06	Pt:	YES (.) what happened um: (.) if we go right the way from the
07		start ↑is (.) round about Christmas there were a bit of blood (.)
08		in the old um: (.) toilet (.) so I went to see the er: (.) the ↑doctor
09		<Doctor (name)> um: ( ) to his surgery=
10	Dr:	=y[eah
11	Pt:	[he had a look ( ) and said it's fine but ↑piles (.)
12		so he gave me some of these er: ↑suppositories is ↑it
13	Dr:	=uhum=
14	Pt:	=and ( ) about three weeks later (.) at five
15		o'clock in the morning there was a massive (.) er: 'aemorrage
16		(.) it gone all over the place
17		((Patient continues to provide additional information))

Following the patient's next turn open class repair initiation (Drew, 1997) (3), the doctor reformulates his prior turn in the form of a statement, but without the query tag "you presented with some BLE↓eding. <some> (.) from your back passage." (4-5). The patient confirms the doctor's proposal, "YES" and expands on his answer (6-16), whilst the doctor offers continuers "=y[eah" (10) and "=uhum=" (13).

The doctor's declarative at lines 4-5 could (sequentially speaking) just lead to confirmation or disconfirmation with correction, as we saw in *3.1*, *3.2* and *3.3*. However, the patient neatly works to first of all tell the doctor that he is doing

'calculation' or considering how to inform the doctor of what happened "um:" and, second, the third part of his turn, "if we go right the way from the start..." (6-7) acts as a story preface and forecasts further talk. In *Extract 3.4*, we begin to see that, through a multi-unit turn, a patient may respond in a way projected by the question type, but may also "break the sequential mould" to provide additional information. On this occasion the doctor is informed that initially the patient was told that his symptoms were a result of "piles" and three weeks later he experienced a "massive haemorrhage". This is hearable as similar to an "atrocity story" of medical incompetence, similar to Baruch's (1981) work on atrocity stories, which will be discussed in the next section (*3.4.2*). For now, I do not want to talk in detail about what this sort of expansion is doing here, but want to simply note at this juncture that responses may accomplish a range of actions, other than responding to the question posed and may be constructed in a 'storied' format. Just as Stivers and Heritage (2001) demonstrated that, "minimal answers in... history taking are not [necessarily] restricted to yes/no-question designs" (p153), so too we can begin to see that expanded answers are not necessarily restricted to 'open' question designs.

Let us revisit what we have viewed so far.

3.4.1.3 A summary

The questions in *Extracts 3.1-3.4* show examples of closed questions, which are constructed as gist statements or candidates, which contain information about the patient journey to the here and now of the consultation. Through the post initial tags the first candidates / declaratives in a series are marked as queries, "is that right" or "didn't you" (see *Table 1, page 70*). Patients align with this history taking activity by producing confirmation / disconfirmation, and on-topic elaborations to provide the evidential basis for their disconfirmations. The features that inhere in the extracts shown and the actions performed can be glossed as follows:

1. These early moments help to familiarise doctors with patient cases.
2. The question shapes described tell patients that confirmation / disconfirmation is required from them.

3. The use of a statement of what has happened combined with the query tag indicates a slight epistemic caution on the doctor's behalf. That is, it is the patient who has experienced the 'journey' first hand, and only s/he can confirm/disconfirm the doctor's understanding. Patients have been shown to use a similar question shape, where the "right?" tag will seek a doctor's confirmation, signalling the patient's recognition of the "tenuous nature of his (sic) offerings" (Beach et al., 2005: p904).
4. Although there is limited explicit opportunity for patients to respond in their own 'words' or at length, patients may make relevant additional material and produce this as part of their answer turn, especially when a correction is required.
5. The question turns display the doctor as a health professional who knows something of his *new* patient. Through such a solicitation act doctors say, 'look we have not met before but I know of you'. This might serve to reassure patients who have seen a number of health professionals by the time they meet the Consultant to discuss radio- or chemotherapy.
6. The doctor's orientation toward his knowledge, but also to the limits of that knowledge (reference to the second hand nature of the information, for example), works to tell patients that their input is required.
7. The doctor's repetition of the corrected material orients to the patient's contribution as credible. This works to sequentially delete the incorrect or incomplete information previously proffered by the doctor.
8. The upshot of these early moments is the accomplishment of a cooperative collaboration where the patient and doctor are allies in the task of establishing a common ground vis-à-vis 'how this patient came to be a cancer patient in the here and now of the consultation'.
9. Overall, however, the approach to question asking described in this section resonates with the canonical view of history taking, as an activity that involves minimal patient input.

More generally, during these initial history taking sequences, information that has no grounding in the clinic is shared and this works to begin to establish a common ground or story before further questions are asked and information exchanged. These extracts nicely illustrate how doctors produce knowledge, whilst making sure that it is

hearably drawn from other people and contexts. The equivocality of *second hand knowledge* invites patients to participate (see Allistone, 2002; this is similar to his observations of parent-teacher evenings).

In most of the cases in the corpus, cancer is not directly introduced as the core subject to be discussed during these early moments; 'it' remains unspecified[19]. This practice is not uncommon and reconfirms what others have shown in other domains where 'dreaded issues' or contentious issues are being managed (Peräkylä, 1995; Silverman, 1997; Beach et al., 2005; Lutfey and Maynard, 1998; Bergmann, 1992).

These moments of finding out how patients 'got here' are part of a slow build toward explicit 'cancer talk'. To do this they need to start somewhere and they appear to start with a 'beginning' of 'the' story, as suggested by the notes they hold or by information gleaned from other doctors.

Next, we consider an alternative approach to establishing a common or shared ground before progressing with the *main* business of the consultation. Patients are not invited to confirm or disconfirm a candidate pathway, but are invited to provide information to augment any information already held.

3.4.2 Open interrogatives: "So how did this all start?"

In *Table 2*, ten open interrogatives are shown. Again, listing them in this way is somewhat unsatisfactory because they are out of their natural sequential environment. Nevertheless, it helps to clarify what I call here 'open questions'. I also indicate what kind of response the questions solicit. Again, I have categorised these as: (1) reply (does not go beyond the information requested); (2) reply plus a brief expansion (the expansion is unnecessary in terms of the project of the question, but includes information that is on topic); and, (3) storied expansion (the patient offers a story preface, normally situating their answer in time, and narrates a journey in chronological terms).

[19] In *Chapter Four*, we will see that and how doctors seek out patient knowledge about or realisation of their cancer diagnosis before proceeding to discuss diagnostic and treatment issues.

It is worth noting again that in *Tables 1* and *2* I have shown the third turn action slot, when the doctor produces one prior to the patient expansion. This gives at least some indication of what (sequentially speaking) leads to some of the patient expansions.

Table 2: Ten open interrogatives

Extracts	*Case*	*Site*	*Question*	*Answer*	*Third position*
3.1	11	H3	↓o↑kay (.hh) and ↑did you ↑find the lump your↓self ↑how did this [all ↓start]	Storied expansion	
3.2	12	H1	r:↑ight now when did you first no↑tice	Storied expansion	
3.3	13	H3	↓o↑kay did you find the lump yourself tell me how this all came abou↓t=	Reply + storied expansion following continuer	Doctor continuer
3.4	14	H1	°o<↑kay>° (1.0) .hhh (1.5) and ↑what sym↓ptoms did you first present to Mr ((doctor's name)) ↓with=	Storied expansion	
	4	H2	Um and the story as I've got it is that (.) this trouble probably all started when you had the thing taken off your cheek	Reply (+ gap) + storied expansion	Gap
	15	H1	Righhhhhhht (.) how- what symptoms did you first present to Mr A?	Reply (+ gap) + storied expansion	Gap
	16	H2	how l↑ong have you ↑had ↓this	Reply	Next questions
	17	H2	HOW LONG (.) HAS YOUR VOICE BEEN (.) playing ↑up?	Reply + brief expansion following doctor assessment	Doctor assessment
	18	H1	Now WHat symptoms did you have initially when you first presented?	Reply + brief expansion following doctor continuer	Doctor continuer
	19	H2	now when did this ↑all: (.) ↓start. you initially saw (.) Dr ↓J is that ↑right	Reply + understanding repair + storied expansion	Doctor confirms patient understanding of what he wants to know

From *Table 2*, it is clear that 9 of the 10 questions generate expansions, with 7 of the expansions resembling stories of a journey to diagnosis (cases 11,12,13,14,15 and 19) and 2 detailing brief expansions which relay a single aspect of the journey to diagnosis (cases 17 and 18). One case (16) results in a reply that does not introduce material that transcends the immediate concerns projected by the question ("I didn't know I had it until after the operation"). All of the expansions attend to the questions,

whilst simultaneously making sub-topical and off-topic shifts to contextualise their reply in a broader story of the journey to the here and now. That case 16 offered a reply can be seen as understandable when the question is compared to the other 9 questions. To be asked, "how long have you had this" is less of a story invite when compared with the other questions, "how did this all start?". Indeed, "how long have you had this" is hearably ambiguous in terms of what it is the doctor wishes to know. Technically the patient cannot be expected to know how long they had 'had this', with "this" presumably referring to cancer.

First, let us briefly consider the question turns in *Extracts 3.1*, *3.2* and *3.3*. I will then proceed to examine the patient responses.

3.4.2.1 The questions

Extract 3.1 (Case 11).

01. Dr: ↓o↑kay (.hh) and ↑did you ↑find the lump your↓self
02. ↑how did this [all ↓start]

Extract 3.2 (Case 12).

01. Dr: r:↑ight now when did you first no↑tice

Extract 3.3 (Case 13).

01. Dr: ↓o↑kay did you find the lump yourself
02. tell me how this all came abou↓t=

Extracts 3.1, 3.2 and *3.3* show question turns that are composed of separate parts or units. Each has a turn initial 'right' or 'okay'. In the same way as questions in *Section 3.4.1* in which we examined the 'closed questions' these signal that the doctor is about to move into a new activity. Following the turn initial, in *Extracts 3.1* and *3.3*, the doctor presents a question about the discovery of "the lump", and the doctor produces another part to the turn with the invitation to tell how this all started, or came about. The question in *Extract 3.2*, although requesting slightly different information, equally invites the patient to 'fill in the gaps' on the first steps of the journey to diagnosis, in particular when they initially 'noticed'; presumably referring to when they first 'noticed' that their body was 'non-normal'. Unlike the declaratives or tag

questions, these open questions request information (akin to category (3) answers discussed earlier).

I do not wish to dwell on the turn construction of these interrogatives. Suffice to say that although the same kind of features of the patient case are topicalised, of how they reached the 'here and now', the action performed through these questions contrasts with that accomplished by the 'closed' questions discussed previously. They invite patients to provide information and not 'yes that is right', 'indeed', 'yeah' or any other of the many variants of confirming / disconfirming or agreeing / disagreeing found in the majority of the closed interrogative cases previously discussed.

I want to spend some time examining the patient responses to these open format information requests. To reiterate, the focus here is to assemble a view of the different approaches to question asking during early history taking, the actions performed by such questions and the kinds of responses these might solicit.

3.4.2.2 The responses

In similar vein to Stivers and Heritage (2001) and others (see Drass, 1982; Peräkylä, 2002; Drew, 2001; Jones, 2001), analysis suggests that although the function and scope of history taking can, because of its agenda driven nature, be constraining, it does not (necessarily) *determine* what patients do. Indeed, the broad characterisation of history taking as an activity that occasions question and answer chains belies the real range of question types and the answers produced in relation to them. In part, a focus on patient answers will provide a glimpse at *patient agency in interaction* and unsettle the blanket view of history taking as a constraining interactional environment.

Patient responses provide an aperture to some of the skilled ways in which they might generate answers to questions, whilst simultaneously orienting to their own agenda of what they (interactionally) require the doctor to know. As well as viewing the depth, length and construction of the questions produced, we see that some of the material proffered by patients can be seen to 'do' work that extends beyond simply answering

a question or producing information. Patient identity work constructs them in particular ways.

We have already seen the possibility that patients may craft their answers to questions by narrating an "atrocity story", such as the story of medical incompetence in *Extract 3.4* (*Section 3.4.1 'Closed Questions'*). As already noted, the work of Baruch (1981) is important to this analysis. Baruch closely examined interview talk with parents with a child attending a paediatric cardiology clinic or being treated for cleft palate/hare lip. He found that parents designed their talk in such a way as consistently to produce moral displays of their parenting skills and this was accomplished through the 'atrocity story' (p278). These atrocity stories worked to produce parents as responsible and not at fault or to blame for their child's condition, which importantly had not been detected for some time. Parents thus worked to answer the unstated question of, "How could you, as parents, have allowed that to happen to your child?"

Related to this, we shall see that patients may account for their actions, of what they did or thought prior to diagnosis, and they accomplish this through narrating what might also be called "atrocity stories". They contrast their 'reasonable' actions with possibly unreasonable actions of health care practitioners. It seems to be the case that when asked to explicate the path to becoming a cancer patient in their own words via an open format question, patients may see this an occasion to rebut a potential charge of blame[20].

Before getting started, a word of warning is required. The extracts in this section are long but this is necessary to demonstrate how, during these history taking moments, answers produced can be long and involve multiple turns. Indeed, they can be likened to illness narratives or stories that one might expect to find in a research interview and not in history taking, as it is conventionally or normatively conceived. Using such long fragments compromises the analytic depth but we gain a broader and vital view of the kinds of questioning and responding work done in the early history taking moments. Let us begin with *Extract 3.1a*, which takes place at H3 and is between a

[20] With a larger corpus, it may have been possible to test this observation in an interesting way by comparing patients with cancer more usually associated with 'bad' lifestyle habits (e.g. lung cancer and smoking) with those that are not so obviously linked with lifestyle causes (e.g. testicular cancer).

37-year-old woman with advanced breast cancer and the consultant oncologist (specialising in chemotherapy).

Extract 3.1a (Case 11).

01	Dr	**↓o↑kay (.hh) and ↑did you ↑find the lump your↓self ↑how did**	← a.
02		**this [all ↓start]**	
03	Pt	[yes I did] ↓yes (.) um (.) around the beginning of M↑a:y er-or	← b.
04		(.) <↑yeah> first half of ↓May I noticed that (.) there was like a	
05		↑thickening (.) >going from< (.) here toward the:: (.) ↓nipple (.)	
06	Dr	↑um	
07	Pt	and I thought it was like a piece of tissue or mu↑scle [and]	
08	Dr	[um:↑mm]=	
09	Pt	=my GP re↑ferred ↓me (.) around mid-May=	
10	Dr	=um↑hm=	
11	Pt	=to the hospital=	
12	Dr	=um↑hum	
13	Pt	(.hh) and I went to ((first hospital name))=	
14	Dr	=umhum=	
15	Pt	=er ↓hospital (.) and ↑the:y (.) on the ↑first day I went there they	
16		(.) straight away said that it could be cancer=	
17	Dr	=mm=	
18	Pt	=after the mammogram and >then< (.) they did a test and er (.) (I	
19		received everything [in one]	
20	Dr	[mm↑m]=	
21	Pt	=↓day) (.) >and< um: (.) <and ↑then um> (.) a↑bout (0.5) erm	
22		then I waited for the ↑results two more ↓weeks	
23	Dr	um↑hum	
24	Pt	and then a week later I was referred (.) ↓here=	
25	Dr	=°um[↓hum°	
26	Pt	[to ((hospital name)) (.) 'cos you were (.) offering	
27		reconstruction [here <↑°so°>]	
28	Dr	[↓yeah:] (.) and you ↑had the reconstruc↓tion=	
29	Pt	=y:↑eah (.) which somehow I:: have (.) mixed feelings about	
30		[(as w(h)ell)](laugh)	
31	Dr	[°o↓kay°]=	
32	Pt	'cos I paid quite a big price for it	
33	Dr	↓what [↑happened]	
34	Pt	[I (had lots)] of post-operative complications	

35 Dr ↑WHAT sort of things did you ↓have

36 Pt I had ↑three ( ) [and]

37 Dr [↓right]=

38 Pt =and four (.) ↑four operations and four anaesthetics in three days

39 Dr so ↑quite a difficult [↓time ↑didn't ↓you]

40 Pt [↑yeah yes::]

41 (1.0)

At the beginning of history taking, the doctor produces an open question that is hearably a story invitation, "↓o↑kay (.hh) and ↑did you ↑find the lump your↓self ↑how did this [all ↓start]" (←a.). The patient begins to provide her answer to the doctor's question, and does so by first offering agreement with the proposal that she found the lump herself, "[yes I did] ↓yes" (← b.) and then following a process of consideration and a micro pause "um (.)..." she begins to narrate her journey to diagnosis. She does so by offering a chronological marker or story beginning, "around the beginning of M↑a:y er-or (.) <↑yeah> first half of ↓May..." (← b.). This skilfully lays the groundwork for a multi-unit turn. That is, the chronological marker forecasts future dates. Her next part offers her perspective on the first cue that something was wrong, "I noticed that (.) there was like a ↑thickening (.) >going from< (.) here toward the:: (.) ↓nipple (.)" (4-5). The patient stays with the 'discovery' topic set by the doctor's question, but informs the doctor that the discovery did not involve a lump per se but a change in the texture of her skin. Thus, even in the space of the patient's first three part turn, we learn something about the patient's journey towards diagnosis, that was not demonstrably known by the doctor in the here and now. The merit of an 'open' question format is thus demonstrated at an early juncture, but interestingly no more so than in the closed replies with correction in *Extracts 3.2* and *3.3* in *Section 3.4.1.*

Following the doctor's continuer, 'um' (6), the patient uses the connective 'and' to produce her thoughts on what the problem might have been, "piece of tissue or mu↑scle [and]" (7). Her use of 'and' again tells the doctor there is more to come by producing her current turn as connected to a next. The patient informs the doctor about her 'referral by her GP' (9) to hospital. To gloss the rest of her narrative telling, the patient continues to talk about the journey from GP referral, to tests and, finally, the hospital in which they are meeting. The reason for the hospital referral is provided,

"and then a week later I was referred (.) ↓here= [((Hospital name)) (.) 'cos you were (.) offering reconstruction [here <↑°so°>]" (24-27).

The patient's use of 'so' in post-initial slot tells the doctor that the upshot to the narrative telling is forthcoming (see Stivers and Heritage, 2001: p174). This is produced in overlap with the doctor's response, "[↓yeah:] (.) and you ↑had the reconstruc↓tion=" (28). The patient could meet the requirements of the doctors overlapped upshot announcement with a simple 'yes', but she expands her answer to produce a "troubles telling" (Cuff, 1980), "=y:↑eah (.) which somehow I:: have (.) mixed feelings about [(as w(h)ell)](laugh)" (29-30) (her laughter may signal some discomfiture relating to her turn, see Haakana, 2001). In overlap, the doctor produces the 'okay' receipt, which works as a continuer and the patient proceeds to give the reason for her 'mixed feelings', "'cos I paid quite a big price for it" (32). Immediately, the doctor invites the patient to provide her reasons for this, "↓what [↑happened]" (33). It is worth noting that often troubles like this are simply acknowledged by doctors and comments held off until later in the consultation (see Stivers and Heritage, 2001; Sacks, 1992). Here, the doctor pursues the trouble and they continue to talk about the complications associated with the reconstruction.

Although a gloss, we can map out the key steps in the patient's story in *Extract 3.1a* below.

a. Early May, the patient noticed that her body was non-normal.
b. Describes symptoms in quite medical terms.
c. Provides own interpretation of symptoms as benign / non-serious 'piece of tissue / muscle'.
d. GP referral to hospital, a couple of weeks later.
e. Visit to hospital involved mention of cancer possibility.
f. Mammogram.
g. Two week wait for results.
h. One week later referral to hospital, where reconstruction available.
i. Had reconstruction but has regrets / mixed feelings about the reconstruction.

In terms of the doctor's response to the story we can see that continuers and small response tokens are provided. The doctor's 'uhm' / 'mmm' tokens perform a "sequential" function, rather than an "interpretive" function (Frankel, 1984) and the doctor is aligned as story recipient. That is, the patient talk is oriented to as a story.

This data extract and those that follow are rich in interesting material, but I want to focus on a few core features. First, in the first part of the doctor's question he offers a cue of where to commence the story, and that is the 'discovery of the lump'. The second part of the question, 'how did this all start' makes less specific the topic to which the patient is invited to speak and possibly draws on the doctor's experience of other patients whose journeys have not commenced with the discovery of a lump but some other symptom. The patient's response takes this cue and she informs the doctor of what precisely she had noticed (e.g. thickening). In similar fashion then, to the extracts demonstrating the closed interrogatives, the doctor proposes a story beginning, but due to the 'open' nature of the question design, the patient works with the story beginning and introduces material beyond the immediate remit of 'finding the lump'. Second, at this point the patient's response is hearably complete in terms of project of the question. However, the doctor's 'um' provides licence for the patient to continue. That is, the doctor orients to the patient's turn as just one of a multi-unit story. Third, as well as the journey to the *here-and-now* of the consultation being narrated, the patient provides her thoughts about part of the journey. She informs the doctor of the difficulties of the reconstruction and the doctor pursues that trouble, rather than proceeding with history taking.

Here we see an exemplar of the open interrogative and how the flexibility created through this and the doctor's continuers is used by the patient to produce information that is relevant to her and not tightly tied to the question of 'did you find the lump yourself' nor to 'how did this all start'. That is, she orients to the doctor's 'how did this all start' as a request for a ('life-world') story.

Overall, the question works to solicit information on how the patient reached the here and now of the consultation and so doctor and patient 'get acquainted' in this way and a common ground is established. Furthermore, the patient provides the first mention of cancer, and so cancer is produced as a mentionable object. Indeed, during the

responses to 'open interrogatives', at least in this corpus, patients are more likely to mention cancer than they are in the closed Q-A sequences. That is, during closed question responses patients (generally) echo doctors' euphemistic descriptors, whilst during open question responses patients produce the object of discussion 'cancer' as a "mentionable" (Bergmann, 1992).

Let us move to another data extract. In *Extract 3.2a*, we again see that the open interrogative results in a lengthy patient turn, which narrates a journey to diagnosis that started some seven years prior. Again, the extract is taken from H3.

Extract 3.2a (Case 13).

01		7.0[21]
02		((Doctor working on computer
03		as patient enters))
04	Dr:	**okay did you find the lump yourself**
05		**tell me how this all came about=**
06	Pt:	=there was no- no lumps=
07	Dr:	=(right)=
08	Pt:	=it started in 1998 y'know pain in both bre[ast
09	Dr:	[yes
10	Pt	and I came here they checked it and they said
11		nothing was wrong=
12	Dr:	=yeah=
13	Pt:	they- they sort of discharged me they sent me a
14		letter they said- they cancelled the er
15		appointment=
16	Dr:	=mm hum=
17	Pt:	=.hhh they gonna send me another appointment
18		<they didn't>=
19	Dr:	=mm=
20	Pt:	=I was pregnant and stuff (.)=
21	Dr:	=mm=
22	Pt:	=.hhh and .hhh just before I came here about two
23		weeks before I came here I found some discharge

[21] The doctor in this consultation told me that it was important to always ensure that the correct page on the computer is showing and basic information entered prior to the patient's entry to the consultation room, so as to limit the 'computer time' during the consultation to enable a focus on the patient. Indeed, since I sometimes collected patients from the waiting room for the consultant, it was my job to check that the consultant (and the computer) was ready to see the next patient.

24	Dr:	from the nipple=
25	Pt:	=yea yeah I found it about- twice or three times=
26	Dr:	=mmm hum=
27	Pt:	=then I went to my GP and he send me and it's
28		cancer
29	Dr:	right so that's been a huge shock for you hasn't it
30	Pt:	yeah

Let us begin by looking at one of the patient's last turns, "=then I went to my GP and he send me and it's cancer" (27-28). For this patient it is not the bad news interview, specific tests and so forth that are central to the plot of the story she narrates into her answer about how this all "came about". Indeed, this aspect of the journey is produced in a contracted form. If we inspect the turn we can see that it is made up of three separate parts; (1) went to GP, (2) got a referral, and (3) cancer was diagnosed. This is an abbreviated or condensed version of a series of events. Contrastingly, central to the patient's telling is the length of the journey travelled towards this point and the difficulty in accessing the health care system. For the patient, the "storyable" part of her journey is the pre-diagnostic journey of how, "=it started in 1998 y'know..." (8), "they said nothing was wrong=" (10-11), "they cancelled the er appointment=" (14-15), "=.hhh they gonna send me another appointment <they didn't>=" (17-18) and so on. All of these story elements orient to the difficulty of getting her "pain" legitimated. This reminds us that entry and exit criteria to the sick role can be (experienced or narrated) as carefully regulated (Tishelman and Sachs, 1998).

The patient sets up a contrast between herself and the health care system. For example, she describes the onset of a bodily change that followed her initial "pain", "discharge from the nipple", and she positions this experience in time, as happening "just two weeks before" she visited the hospital in which this consultation is taking place. She also notes that she was pregnant ("and stuff") (20); with the 'stuff' possibly implying that she was legitimately preoccupied with being a pregnant woman and hence less able to pursue a referral. She recurrently narrates other key players into her story as 'they', with 'they' representing the health-care system where 'they' failed to fulfil a promise and organise a timely appointment. Implicit, then, in the patient's narrative response is a complaint about her vacillating and protracted path to diagnosis and to the here and now. She simultaneously casts herself in a morally

adequate light, as a reasonable and responsible individual who sought help in the first place when she found her body to be non-normal. Again this resonates with the work of Baruch's (1981) informants.

The patient skilfully contrasts her protracted search for help / medical attention with the sudden diagnosis delivered some time later, "=then I went to my GP and he send me and it's cancer" (27-28). Like the previous example, the patient makes relevant some atrocious matters. Atrocities are highly 'storyable', especially where the storyteller is not the 'guilty' party. The doctor aligns with the import of the patient's story and in the upshot utterance, "right so that's been a huge shock for you hasn't it" (29) displays an understanding of the shock of a *sudden diagnosis* vs. a previous *GP and hospital visit where "nothing was wrong"*.

This patient answer contrasts quite starkly with the responses reproduced in the earlier extracts where confirmation and disconfirmation were the key actions performed. In *Extract 3.2a*, critical insight into the patient's preoccupations is provided (Stivers and Heritage, 2001).

The final example in *Extract 3.3a* shows another open format interrogative being deployed and responded to. The patient stays with the project of the question, whilst exploiting the opportunity to topicalise her thoughts and feelings, including her concern about bodily changes prior to diagnosis.

Extract 3.3a (Case 12).

01	Dr:	**r:↑ight now when did you first no↑tice**
02	Pt:	um I had a problem in the ↓summer (.) in July (.) when I (.)
03		be↑lieve I had >knocked< my nipple (.) an:d it didn't ↑heal
04		very much (.) <it ↑wasn't> par↑ticularly I-I-I'm sure I did (.)
05		catch it on the end of the ↑end of the bed=
06	Dr:	=right=
07	Pt:	= .hhh I ↑saw the G↓P (.) I felt a↓round quite a ↑lot and (.) I
08		didn't feel anything ↓odd (.) and when I actually saw the
09		G↓P (.) who ↑was (.) re↓assuring (.) <did a> breast
10		examination. (.) and (.) (y'know) and didn't find anything
11		unto↓ward (.) and I ↑then (.) didn't do anything ↓more (.)

12 until ( ) (.) then I went ↑BACK to ( ) (.) the
13 A↑CTUal nipple area didn't get (.) much ↑worse <at all> it
14 Jus:t didn't do ↑anything [rea]lly
15 Dr: [right]
16 Pt: (.) but (or something it would <sort of>) go
17 A↓way (.) it was ↑LIKe a tiny patch of e↓xcema (.) that's
18 (simply) all: I would ↓describe it as. (.) it wasn't
19 dis↑charging, it wasn't (.) it was nothing like ↓that (.) ↑SO
20 (.) I ACTUALLY ↑MADe an appointment and then
21 can↓celled ↓it (.) I-I-I-I was <sort of> un↑happy but (.)
22 <sort of> I kept re-assuring myself=
23 Dr: =right=
24 Pt: ='cos I didn't actually feel anything (.) um: abnormal. (.) I
25 ↑went to the GP again (0.5) it must have been (.) oh time's
26 rather rushed now (.) it must be >a↑bout:< three or for weeks
27 A↑go (.) <about> the middle of January (.) <and she was
28 con↓cerned> (.) e↑nough to ↓say that I needed to go (.) to
29 the b↓reast (.) ↑clinic (.) an:d m:y sense is that she's not a (
30) she ex↑amined (.) <and ↑then she ↓did> (.) actually (.) and
31 I rang her the following (day) and she said to me that she
32 was surprised I hadn't °felt it° (.) ↑um MY under↑standing
33 (.) then I phoned (.) ↑CAMe to ↓breast ↓care clinic. er: had
34 A bio↑psy (.) the lump was obvious on mammogram (.)
35 <quite ↑biG> (.) um: (0.5) and
36 ((Patient continues))
61 =is that o↑kay
62 Dr: that's absolutely fine. (.) .hhh ((doctor continues))

As with the previous extracts *3.1a* and *3.2a*, the first part of the patient answer situates her story in time when she offers the chronological marker "um I had a problem in the ↓summer (.) in July" (2). She then produces a proposal of the start of the problem when she knocked herself on the end of the bed (5). The patient opts for a course-of-action approach in her telling, where she describes what she did (and why) and the GP's actions (and why). For example, at line 7 she produces the following multi-part turn, ".hhh I ↑saw the G↓P (.) I felt a↓round quite a ↑lot and (.) I didn't feel anything ↓odd (.) and when I actually saw the G↓P (.) who ↑was (.) re↓assuring (.) <did a> breast examination. (.) and (.) (y'know) and didn't find anything unto↓ward (.)..." (7-11). Here the patient narrates another 'atrocity story' in which a further instance of primary medical care neglect is integral. Again,

in and through this telling, the patient casts herself in a morally adequate light, as someone who sought medical advice when faced with bodily changes and whom followed expert advice when she was "reassured" and nothing "untoward" was found. Clearly, I have fragmented the patient's multi-unit turn, but this allows us to block this rich sequence out and delve into the work that the patient is doing here.

Continuing with *Extract 3.3a*, at the start of her turn at line 7, the patient produces an in-breath at the beginning of her utterance, which is commonly produced at the beginning of a turn; it works to say 'I am about to speak'. She states that she saw the GP and the next part is hearable as a parenthetical comment, "...I felt a↓round quite a ↑lot and (.) I didn't feel anything ↓odd (.)...", which tells the doctor that she is a woman who self-examines. The parenthetical insertion links back to the patient's prior turns about the change in her nipple, which she has already accounted for as being a result of a knock. Thus, she portrays the initial discovery as linked to a benign cause, a knock, with no immediate action required. The patient proceeds to narrate her journey when she notes the visit to the GP, "...and when I actually saw the G↓P (.) who ↑was (.) re↓assuring (.) <did a> breast examination. (.) and (.) (y'know) and didn't find anything unto↓ward (.)..." (8-11). Here the patient's own results of self-checks are corroborated by the GP's reassurance.

Following this result, the patient informs the doctor that she took no further action and that the nipple area did not change, "...the A↑CTUal nipple area didn't get (.) much ↑worse <at all>..." (12-13). Her use of the descriptor "much" implies that some change did in fact occur and she softens or mitigates this by bolstering the 'no problem' line with, "...it jus:t didn't do ↑anything [rea]lly..." (13-14). In so doing she casts her action as a reasonable course of action, both in light of her prior talk – *GP visit and reassurance* - and her next utterance – *no significant bodily change*. In fact, following the doctor's "right", the patient does more work to show that any change that did occur was minimal, "...it was ↑LIKe a tiny patch of e↓xcema (.) that's (simply) all: I would ↓describe it as (.) it wasn't dis↑charging, it wasn't (.) it was nothing like ↓that (.)..." (17-19). This may be seen to continue to cast the patient in a morally adequate light. That is, she is a responsible person who, in the face of seemingly benign changes, took what can be categorised as appropriate action i.e. waiting. Indeed, she proceeds to say how she cancelled an appointment with the GP because there was no change, "...I-I-I-I was <sort of> un↑happy

but (.) <sort of> I kept re-assuring myself=" (21-22). Following the doctor's "right" she reiterates her rationale for the cancellation by stating again that there was nothing abnormal (24).

The patient's story changes tack at line 25 as she begins to inform the doctor that she then returned to the GP in mid-January, which would be approximately six months after her initial "July" visit. The outcome of the visit is described, "...<and she was con↓cerned> (.) e↑nough to ↓say that I needed to go (.) to the b↓reast (.) ↑clinic (.)..." (27-29). Here we have a dramatic turn around from absolutely nothing wrong (repeated on a number of occasions in different ways, combined with reassurance from a medical practitioner) to a medical practitioner's concern and an implicit assertion by the GP that the basis of her professional concern should have been patent to the patient, "...and she said to me that she was surprised I hadn't °felt it° (.)..." (31-32).

Here the patient produces a story and it is a story of waiting, one of ups and downs, of having the *all clear* and then having a lump that is big, so much so that it is surprising to a medical practitioner that she could not feel it. This story is one that is constructed over a number of turns and comprises some repetition of core messages; "I didn't feel anything ↓odd", "the G↓P (.) who ↑was (.) re↓assuring", "didn't find anything unto↓ward (.)","the A↑CTUal nipple area didn't get (.) much ↑worse <at all>", "it jus:t didn't do ↑anything [rea]lly", "it was ↑LIKe a tiny patch of e↓xcema (.) that's (simply) all:", and "I would ↓describe it as. (.) it wasn't dis↑charging, it wasn't (.) it was nothing like ↓that (.)". In other words, the patient does a huge amount of work to discursively invoke a 'no fault' scenario and a scenario in which 'no action taken' can be heard as reasonable by the consultant oncologist.

Extracts 3.1a, 3.2a and *3.3a,* demonstrate how patients can and do weave material into an answer which signals their "preoccupations", contiguous with attending to the project of the questions posed (Stivers and Heritage, 2001). They narrate quite dramatic events in notably non-dramatic terms, thus invoking an orientation to the 'institutional mantle of the occasion' (Maynard, 2003). This is despite the deeply consequential nature of the storied 'delay' encountered in the journey to diagnosis.

Patients subtly indicate how they reached the here and now and what, for them, were the 'memorable' times along that path, whilst averting any sense of direct complaint

or criticism of the health care system or, importantly, of themselves. Such lay identity work is clearly not unique to these cancer meetings. Indeed, Baruch's (1981) classic study showed how parents defended their parental roles by invoking their shock and upset at discovering they had a sick child. What is crucial for this analysis is that this sort of work gets done during the early history taking moments. History taking, often characterised as occasioning rapid-fire Q-A sequences, may also consist of complex patient work. Through their extended answers patients assist in the establishment of a "common ground" and further history taking is undertaken from a shared storied 'beginning' that is mutually understood.

Extract 3.4a provides a more accessible (shorter) example of this. Again, the open question format provides for an extended patient turn, in which another tale of atrocious matters is narrated. As I already noted, atrocities make good stories. Moreover, the use of such a format may attend to the fact that the patients' audience is more 'senior' or 'specialised' than the reported offender(s) and so will want to hear about such matters and will be in a position to (silently) judge them.

Extract 3.4a (Case 14).

01	Dr:	**°o<↑kay>° (1.0) .hhh (1.5) and ↑what sym↓ptoms did**
02		**you first present to Mr X ↓with=**
03	Pt:	= umm:: (3.0) well I ↑first complained to my G↓P (.) about
04		not being able to clear my bowels. (.) a:nd he twice (.) told
05		me it was constipation er: but t-the ↓third time (.) uhm he
06		did a (.) check of the back passage and he said that there
07		some <sort of> obstacle there (.) then uhm (.) I had my first
08		appointment ↓he:re (.) and the doctor that uhm (.) ↑saw me
09		uhm <he simply> ↑said that (it was) (.) a cancerous
10		tu↑mour and ( ) and (to) have to e um: re↓moved.

I will not discuss this extract in any detail. From a superficial reading of *Extract 3.4a*, together with *Extracts 3.1a, 3.2a* and *3.3a*, we can see that the open interrogatives of 'how did this start' or 'come about' result in material that transcends the clinical. Drew (2001) recently summarised a collection of papers that demonstrate:

> ...[P]atients are not docile, but have agendas of their own, which they pursue, through various communicative strategies, through the interaction.
>
> p263.

In these history taking sequences doctors are privy to information, which provides insights into patient life worlds, their thoughts, feelings and concerns *prior to diagnosis* and into their morally adequate courses of action *prior to diagnosis.* Baruch's work on moral accounts in interviews, together with Sacks' (1992) comment about how stories are constructed and the constituent parts carefully chosen, are useful in helping us understand the work that gets done during early history taking moments and the significance of this work.

As with everyday life there may be topics that are 'dear to our hearts' or particularly 'newsworthy', which we would like to discuss. Members constantly monitor for opportunities to be able to raise such topics. Here, we see how open questions may provide an aperture for patients to describe what can be glossed as difficult journeys to a diagnosis; journeys where multiple visits are made, bodily changes seemingly benign and described as such and later described as cancerous. The question of why are these topics important is an interesting one in the broader context of cancer and ill health.

Increasing pressure through the discourse of patient centredness, user involvement and in more general terms a consumerist philosophy to health care places patients centre stage. Patients are 'given' and charged with the right (and responsibility) to seek out the most effective health care when ill health threatens. Indeed, some time ago Parsons (1951) spoke of the obligation to seek professional help when sick. Moreover, discourses of healthy living, through correct nutrition and exercise regimes seem to propagate the view that ill health (especially cancer) can be averted, prevented or delayed if individuals act 'responsibly'. The recent NHS 'Expert Patient Programme' now formalises these sorts of expectations of 'expert patients'. Fox (2005) summarises some of the core aims of self-management courses offered via the programme. Three of these are as follows:

1. Recognising, monitoring and responding to symptoms.
2. Adopting appropriate aspects of lifestyle including health diet, exercise and relaxation, and not smoking.
3. Seeking information and using community resources.

[Source: Fox, 2005: p1306].

Patients orient to these matters in their answers. Formalising patient roles in documents like that above creates a contractual (and moral) commitment with which people are expected to comply. This context may be important in helping us understand the narrative lengths that patients go to in these meetings to come across as individuals who acted reasonably. These 'expert' initiatives, although laudable, potentially place further pressure on those who have cancer to account to themselves, "why me, what did I do wrong?" and to others, "what did you do to get cancer?".[22] Speculatively, then, with these distal pressures (and the local in situ pressure to narrate a storyable journey to the here and now of the consultation), patients may draw these related distal concerns into their stories and work to come across in a morally adequate light to the person who, for the next six months and beyond, is responsible for securing them a cancer-free status. More than that, speculatively, the answers may signal a discursive appeal to the Consultants to 'take care of them' since they have already had a difficult journey.

3.5 Discussion

In this chapter we can see that once the first move to business has been accomplished, doctors invite patients to tell them how they commenced their cancer journey in one of two ways. Either using the 'open' or 'closed' interrogative. Both question types require some kind of answer from a patient because of adjacency considerations[23], but we have seen a quite marked distinction between the types of answers produced. Unfortunately, the size of the data corpus imposes limitations on the generalisability

[22] Indeed, although tangential to the empirical concerns here, during interviews with cancer patients, I frequently noted the efforts that patients went to in their talk to abrogate responsibility for their cancer diagnosis and their search for reasons as to why and how they could have cancer when, for example, they practiced yoga for years, ate five portions of fruit and vegetables every day or attended the doctor on repeated occasions.

[23] Adjacency Pairs are "... a two-utterance, adjacently placed sequences, which are massively present – directly and through expansions – which are used for a whole range of types of organisation for conversation..." (Sacks, 1992: Volume 2, Part VIII, Spring 1972, LC 1: p532). Here we are speaking of the Question-Answer AP.

of the claims that can be made about the Q-A patterns described. It seems fair, however, to note that the more obvious open interrogatives are more likely to solicit detailed material from patients than are the closed interrogatives.

Open interrogatives provide the (sequential) opportunity for patients to frame their journey to diagnosis in their own terms. Patients use the opportunity to produce a 'story' of their journey. As Brown (2003) suggests, "stories are our most natural way to order our experiences and to make sense of them" (p514), whilst fitting descriptions of experience into fixed choice or closed response sets are not.

In the course of their answers patients hearably make a concerted effort to *tell* and to *tell* in particular ways. Story telling is an interactional business and one story may vary in its construction and core plot according to the audience. Patient answers do not represent, 'just another description put in there for the hell of it' (Sacks, 1992: Volume 2, Part 1, LC1: p12). Anyone providing an answer will review the "tellability" of that answer. Whatever is 'put in there' is for a reason and I hope to have specified some of these reasons.

Patient descriptions may be woven in such a way as to reveal a hitch in the fabric of the journey to diagnosis, where doctors first of all produce a no-problem diagnosis or do not refer because of the 'benign' nature of the patient complaint. These tellings work to rebut any potential charges of blame on behalf of the patient, for not attending a health care practitioner sooner, for example. Patients then skilfully underscore their own moral adequacy by implicitly contrasting their course of action with that of the health care brokers. A careful balance is struck in their answers and explicit criticism is avoided, they thus maintain the credibility or "narrative fidelity" of their talk (Czarniawska, 2004). To offer up an account that is too explicitly critical would produce a more patently partisan telling, where an alternative possible account (that of the general practitioner for instance) may be more obviously missing and be required to judge the reasonableness of the patient's own account or story of how they reached the here and now (Czarniawska, ibid).

Although the questions described are doctor initiated and (interactionally) at the disposal of doctors to deploy and not the patients (Roter et al., 1988), the work that

patients do in next position is critical to the project of the questions being realised[24]. That speakers may exploit a turn allocation to produce a telling which attends to the question and does so in such a way as to simultaneously attend to how they 'come off' is not unique to these meetings (Baruch, 1981; Stivers and Heritage, 2001). Indeed, Drew (1998) also reminds us that all descriptions may 'do' moral work and designedly so:

> Insofar as descriptions are unavoidably incomplete and selective, they are designed for specific and local interactional purposes. Hence they may, always and irretrievably, be understood as doing moral work – as providing a basis for evaluating the "rightness" or "wrongness" of whatever is being reported. Additionally, our accounts may themselves be evaluated in those terms, that is, in terms of the propriety or fairness or justice or accuracy with which we have reported some (external) events, or our motives in doing so.
>
> 1998: p295-296.

Even though the "moral work" might not be 'unsurprising', it is of great interest that central to the plots crafted by patients are moments prior to diagnosis where the 'bad news' moments hardly feature. Their stories signal difficulties of getting recognised as people with potentially serious illness, where the waiting for diagnosis is a central feature of the journey to diagnosis and remains pivotal to how they recount their journey to a health care professional whom they have never met [25].

Closed interrogatives project a more tightly specified set of relevancies, to which patients are sequentially 'obligated' to accept or reject and correct. Overall, this 'closed approach' is treated as a 'no problem' way to proceed by patients. They respond and elaborate when invited to do so and (more rarely) when not invited to do so. As Stivers and Heritage (2001) proposed from their single case study, a patient

[24] "We are beginning to recognize 'lay' knowledge as a complex, differentiated entity... We are talking here of expert-knowledge-in-action". Sarangi: 2001: p3.

[25] Interview studies have begun to identify similar stories running through patient answers about 'how this all began' (Leydon et al., 2003). There is also evidence that the act of telling a story may be of therapeutic value and a key "coping strategy" for cancer patients. One common storied approach is that of the "horror narrative", which is thought to signal an initial stage of dealing with a cancer diagnosis, which may be a prelude to "narratives of suffering and surviving" (Carlick and Biley, 2004).

may 'break the sequential mould' and weave their own material into their answer in the "service of their own agenda" (p180).

Doctors disproportionately have speaker initiative in their favour (i.e. they get to ask the questions) but this must not be viewed as unfailingly constraining patients. As Robinson (2001) has argued, "speaker initiative" and "utterance constraint" are two variables which have been conflated in much of the literature (p20) and he shows us how such broad characterisations belie the range of work that gets achieved in the primary medical meeting. I hope to have provided further examples of why such assumptions may in the end only serve to downplay or underestimate the skilled work that patients do. They may pursue their own agendas whether responding to open or closed questions, but the former of these generally seems to provide greater opportunity for the pursuit of their own issues.

We have considered the depth and character of patient answers, but what of doctors' responses? Unlike Stivers and Heritage's (2001) case study, some of the examples used in this chapter show that doctors can and will affiliate with the patient life-world narratives or minimal expansions. This is most evident in the open interrogative sequences where the narrative is more obviously invited. For example, in *Extract 3.2a (Section 3.4.2.2)*, when the doctor marks and recognises the end of the patient's story by producing the upshot of the patient's telling, "so this has been quite a shock for you" and in *Extract 3.2 (Section 3.4.1.2)*, where the doctor pursues the patient's trouble regarding her 'mixed feelings' about her breast reconstruction. Where such affiliation or acknowledgement work is lacking, doctors may be held to account.

In cancer meetings, Beach et al (2005) found that doctors were not receptive to patients' "life-world" concerns. They attended to them but were only "minimally receptive" (p906). In this Chapter we can see that doctors respond to patient's extended responses in various ways and sometimes this will be what we might call 'empathic'. Either way, following Carlick and Biley's (2004) review of coping in the domain of cancer and the role of narrative as central to that process, then it might be the case that, regardless of a recipient's response, the act of narrating a cancer journey might in itself hold some 'therapeutic' value.

Moreover, affiliation may be accomplished on a more subtle level and not just through the obvious uptake of some aspect of the storied material. For example, doctors' affiliation is often evident in and through the very act of recognising the patient talk as 'story talk' and not, for example, querying the points that the patient is making. As Svennevig (1999) reminds us different kinds of evidence exists in talk that demonstrates collaboration and understanding. For example:

> *Assertions of understanding* are accomplished via continuers, such as 'uh huh'.
>
> *Presuppositions of understanding* are evidenced in the recipient initiating a 'relevant next turn'.
>
> *Displays of understanding* are achieved through '(partial) construal of the previous turn'.
>
> *Exemplifications of understanding* are observable through 'paraphrases and repetitions of the previous turn'.
>
> [Source: Svennivig, 1999: p58]

Although we have not focussed on doctors' receipts in any detail, it does seem that these collaborative and understanding markers are (generally) evident in the extracts reproduced in this chapter. When they are not, the open question format is oriented to by patients as a licence to continue, as is the doctor's non-interruption. More generally, the orderliness of the cases dealt with suggests a level of affiliation and this flows from the fact that the answers provided are, 'specifically intended by the teller and collaborated in by the recipient' (Sacks, 1992: Volume 2, Part IV, Spring 1970, LC 2: p227).

What of the consequences then for doctors' work? Stivers and Heritage (2001) suggest the work required of a doctor when presented with narrative data is possibly greater or more difficult than that occasioned by closed interrogatives and tightly specified answers.

> The need to progress the business of the interaction, and the primary mandate to orient to its medically relevant aspects, recurrently pose a dilemma for the doctor in responding to patient expansions. This dilemma is at its sharpest in the case of narrative expansions. In ordinary conversation, by contrast, narratives are overwhelmingly responded to with assessments, appreciations, and second stories. Thus narratives in the history-taking context can pit the normative pressure for response against the demands of the task in a much sharper way.
>
> Stivers and Heritage, 2001: p180.

In contrast to the primary care setting analysed by Stivers and Heritage (2001), the meetings here involve more serious conditions in the secondary care setting of a cancer clinic. Moreover, doctor's questions may seek out the narrative tellings in order to ensure they are properly acquainted. We shall see that the long patient turns build the foundations for further cancer talk. In addition, we have seen that the material proffered by patients may inform doctors on a level that they might not bargain for when posing their questions, that is, in the same vein as Stivers and Heritage (2001) 'life world' material may be 'leaked' or quite explicitly offered up and made relevant by patients. The embedded or manifest agenda invoked in and through the longer narrative material can be used or pursued in the next turns or held for future reference (Stivers and Heritage, 2001). Quite simply, the information is not just permissible (in interactional terms) but may prove to be eminently usable and useful.

Rather than narrative responses and open questions producing difficulty, closed interrogatives run the risk of missing information that may be germane to and helpful for patient management (even if remembered and used at a later date and not specifically responded to in situ, Stivers and Heritage, 2001). Moreover, in terms of the actual interaction, we saw the potential for doctors to proceed along lines that are quite tangential to the 'history' owned by patients, and getting to the 'correct' version through declaratives / candidates and tag questions can take time. Rapley (2001) elucidates the intrinsic utility of an open question in the research interview in appealingly simple terms[26]. Overall, it would seem that the same could be said of history taking in cancer clinics.

[26] I have substituted the words interviewer and interviewee for doctor and patient.

> By enabling [patients] to produce multi-TCU [turn construction unit] answers, [doctors] enable [patients] to mention a lot of different things. In this way [patients] are 'helped' to produce 'detailed' and 'comprehensive' answers.
>
> Rapley, 2001: p115.

Whether the open or closed interrogative path is pursued, analysis suggests that the task of history taking is pursued and the agenda upheld. Both severally function to constitute and inform the ongoing interaction and allow doctor and patient to 'get acquainted' and establish a common historical ground. Silverman (1997) also found that in HIV pre-test meetings one of two approaches to opening up the talk about the client's risk status would result in the same outcome or endpoint being reached.

Whilst a primary function of history taking is to solicit a patient's medical *history*, doctors also treat it as an opportunity to ensure that parties to the talk are 'on the same page' before diagnostic detail is elaborated and treatment options (chemotherapy / radiotherapy) explained. A certain caution resides not necessarily (or only) around the term or subject of cancer but in doctors' attempts to ensure that the patient journey to the here and now is clear before proceeding. These are extended greetings between two strangers, who are to work towards becoming allies in the difficult activities of diagnostic embellishment, treatment talk, and possible projections about prognosis.

This examination of the early history taking phase (in this chapter) when combined with the following *Chapter Four* will assist in providing a detailed archaeology of history taking in outpatient oncology consultations. In building a description of the various questions and answers we can begin to dig beneath the surface to move beyond broad characterisations of history taking as an activity accomplished through just *questions* and *answers*, to recover the range of questions posed and answers provided, their texture, position, composition and function.

In the next chapter (*Four*) two more elicitation acts are considered. Once these have been described, the observations of this (*Chapter Three*) and the next chapter (*Chapter Four*) are discussed.

4.

Establishing what patients know

> '[D]esign your talk to another with an orientation to what you know they know'. And that maxim has special functions at the beginnings of conversation. There, it's occupied with a particular job, which is re-finding each other. In order to have my mind oriented to what I know you know throughout the course of a conversation so as to tell you things about what's happened to me that you don't know, and not things you know, I have to find who you are, in the sense of what sorts of things I [or another] already told you.
>
> Sacks, 1992: Volume II, Part VIII, Spring 1972, LC 5: p564.

4.1 Organisation of this chapter

This chapter is organised into two sections. *Section 4.3* again examines open questions (OQs). This time, the questions are deployed a little later in history taking, and they seek to solicit patient understandings of their cancer, gleaned from discussions with other health care professionals.

The question sequences vary in terms of their positioning and this, in turn, appears related to doctors' third turn treatments of the patient responses. The OQs deployed at earlier junctures tend to result in the continuation of history taking in the Interview Format (IVF). That is, the third turn action slot is comprised of further doctor questioning. The OQs deployed at later (pre-closing) history taking moments tend to result in a shift to Information Delivery (ID) (see Silverman, 1997). That is, the third turn action slot is comprised of doctor produced assessment / acknowledgement, together with ID. To be clear, we deal here with OQs deployed during history taking as one phenomenon (*Section 4.3 and subsections*), but deal with two differential treatments of the patient produced answers.

The second *Section 4.4* of this chapter briefly describes the deployment of a summarising intersubjectivity marker or what I have called a *Summative Knowledge*

Proposal. Although not question implicative the proposal implicates or presupposes a shared knowledge that cancer was indeed found and operated on. Proposals do not solicit detail from patients, but petition for patient alignment, prior to diagnostic embellishment and treatment talk.

The OQs and Summative Knowledge Proposals are deployed in combination and in isolation during history taking. The chapter ends with a conclusion based on observations made in this (*Four*) and the previous chapter (*Three*).

4.2 Introduction

Just to recap, one of the central tasks in the treatment focussed meetings is to discuss chemotherapy or radiotherapy. In order to do so, doctors (demonstrably) orient to ensuring that a 'common ground' is established, prior to the move towards diagnostic embellishment and treatment recommendations. A large part of ensuring a common ground also involves establishing what patients know about their cancer. We will see that a variety of ways exist to establish such knowledge, all of which involve careful work to manage the potential practical problem encountered in meetings between unacquainted interlocutors:

> Taking too much for granted may give the impression that the speaker is not attentive to the informational needs of the hearer; that he is elevating himself or denigrating the other by 'talking over his head'. On the other hand, presenting information explicitly that is already in the hearer's background knowledge may appear as an underestimation of his intellectual capacity and may thus seem patronizing.
>
> Svennevig, 1999: p62

There appears to be a recurrent pattern in how this work gets done. First, doctors solicit information from patients. The questions deployed tend to seek information that helps to demonstrate patients hearably 'own' their diagnoses; they are aware that they have or have had a cancer and exhibit a preparedness to discuss this further. Second, doctors summarise what has been established via an intersubjectivity marker or a 'knowledge proposal' such as, 'as you know you had a cancer'. Only then do they

(generally) move forward in a stepwise fashion to diagnostic and treatment informings.

As we have seen, sometimes the information produced by patients in response to open interrogatives like those discussed in *Chapter Three*, e.g. 'how did this all start', provide evidence that a patient knows about their cancer diagnosis. When this is not the case, and indeed even when it is, doctors may endeavour to determine in greater detail what it is patients understand about their diagnosis and they recurrently do this by asking what previous doctors have told them. That doctors might not assume patients 'know', despite the fact that most patients have already commenced their treatment with surgery makes sense when placed in the context of the findings of other studies.

Phungrassami et al. (2003) investigated 'disclosure' of a cancer diagnosis to patients in Japan. They found that just over 62% knew their cancer status, whilst the others reported not knowing what was wrong. Importantly, the patients included in Phungrassami et al's (ibid.) study were about to embark on radiotherapy or chemotherapy, as were the patients included in the study reported in this thesis. Phungrassami et al. (ibid.) comment on the relation between stage of treatment and 'ownership' and knowledge of a cancer diagnosis.

> Receiving more treatments or meeting more oncologists was not associated with a higher likelihood of knowing the diagnosis.
>
> p1680.

There is, then, a cautious epistemics to the work reviewed in this chapter and this is hearable in two key ways. First, as already implied, cancer itself is (sometimes) treated as a delicate object. Doctors seek confirmation that their conversational partner has already adopted the identity of 'cancer patient'. Doctors' questioning is designed to check that patients 'own' their diagnosis of cancer and this facilitates the delivery of news that is tailored to patient knowledge or understanding. Second, during their answers, patients observably seek to ensure that their reports are 'dressed' as lay renderings of expert tellings. This approach to answering the doctors' questions invokes epistemic caution on patients' behalves. This compares to how doctors also

work to show or display that their knowledge held about patients is second hand in nature; derived from patient notes or talks with other doctors (as in *Chapter Three*) and as evidenced in their requests to hear what other doctors have told them (in this *Chapter Four*).

The work of Maynard (1992, 2003) is key to understanding the type of questions deployed. Some of his work demonstrates how doctors gather information from patients in potentially sensitive domains. Maynard established the power of a single 'open' question to solicit information from patients or parents of children with developmental difficulties. And, in similar vein, in the meetings considered in this thesis, doctors solicit information about diagnosis, surgical procedures and, sometimes, prognosis.

We will see that information provided by patients occasions two key next activities from doctors: (1) the continuation of history taking with more questions and (2) acknowledgement, evaluation of the patient turn and a move towards ID. First, I deal with the former. I then discuss the latter type, cogently described as a 'perspective display' strategy or series, which is available to clinicians who wish to solicit a patient view prior to delivering their own (Maynard, 2003). Although the former sequence (1) (similar to *Chapter Three*) can be broadly characterised as question-answer (Q-A) couplets, lengthy patient turns do ensue when answering doctors' questions.

Again, patient answers sometimes work to reveal information that can be considered to 'transcend the purely clinical' (Stivers and Heritage, 2001). Patients continue to play a central role in the information *exchange* that takes place during history taking. The Q-A machinery, though powerfully asymmetric in the sense that the doctor in the questioning role can exploit the 'repeat' rule that inheres in the role of questioner, history taking only *appears as history taking* and is accomplished as history taking, "through the cooperative activity of [all] participants" (Silverman, 1998: p164). It requires that patients speak up and, as we shall see, they do so, and in highly specialised ways (see Sarangi for a discussion of 'expert laity' 2001).

Analysis begins to provide evidence that the secondary care cancer meetings considered in this thesis exhibit a different texture or quality to many of the primary

medical care encounters previously reported in the literature. As Rogers and Todd (2002) point out, although the literature on doctor-patient communication is vast many studies use interviews or surveys to gather patient and clinician attitudes on these issues. Moreover:

> ...[T]hese findings are not necessarily applicable to doctor – patient interactions in oncology... Oncology consultations are more specialised, serious, complex and frightening.
>
> 2002: p337.

The significance of 'disease' type must not be overplayed, but it is entirely possible that the chronicity or severity of an illness may inform the degree to which patient involvement becomes central to the interactional achievement of the consultation. Acute medical visits involve an entirely different patient management, from problem identification through to management of the identified problem.

'Gold standard' texts and training programmes often call for doctors to do more 'open questioning'. In this chapter we see how particular types of Open Questions (OQ) work and view the range of doctor and patient practices that go towards the accomplishment of OQs and the 'closed' Summative Knowledge Proposals. Again I must note here that I label questions simply as Open as a 'way in' to analysis, some order of categorisation of this kind is required. Such categorisations must not be taken to delete or avoid the importance of the turn-by-turn unfolding of the sequences of talk discussed. That is, it is not the case that if a question is 'open' it unfailingly 'determines' what happens next and sets in motion a particular series of actions. Rather, the way in which an open question is formulated, or whether an initial answer-turn by a patient is followed by a continuer, a silence or a next question, for example, are all matters of significance when thinking through different question types and these features of the talk cannot (and are not) ignored.

4.3 Examining the 'Open Question': "Can you tell me what Mr X told you after the operation?"

Let us view some data extracts to begin to grapple with how doctors move from questions about patient journeys to the here-and-now (*Chapter Three*), to directly request information from patients about the knowledge already gleaned by patients about their illness.

Extracts 4.1 and *4.2* illustrate how the doctors seek to solicit information from patients[1]. Both extracts occur shortly after the questions shown in *Chapter Three*. Cancer remains an unspecified object in the following (simplified) extracts.

Extract 4.1. (Case 1).

01 Dr: what did Mr X say to you after the operation about what he'd found

Extract 4.2. (Case 2).

01 Dr: what did the surgeon say to you after the operation

In *Extracts 4.1* and *4.2* the OQs solicit information about the patients' conditions (not shown). It is frequently the case that doctors access what patients know by requesting them to report what other health professionals have said prior to the here-and-now of the consultation. This approach resonates with that found in *Chapter Three*, whereby the first move to business involved doctors telling patients that they have, "heard something about them through Mr X" or that they "have their notes and have read something about them". All methods orient to a dynamic patient journey that transcends the here-and-now of the consultation, and work to invoke the broader medical team and cancer services.

[1] The majority of fragments in this section are drawn from H1 because the majority were first meetings and this particular chapter, as with *Chapter Three*, is concerned with understanding how two interlocutors who have not met previously 'get acquainted' or establish a mutual understanding of what has happened, to permit the larger project of the meeting to be realised. Again, *Appendix V* can be consulted for details of the cases used and hospitals from which they are drawn.

In much the same way as the open interrogative examined in *Chapter Three,* in asking the questions, the doctor tells the patient that this is a moment for 'my thought talk' (Rapley, 2001: p209) or in these cases *'my-thought-talk-on-what-I-understand-or-recall-from-what-the-surgeon-has-told-me'*. Let us view how the talk continues following the doctor's OQ or 'perspective invitation'.

In *Extract 4.3* below (continued from *Extract 4.1*), the patient answers the doctor's question (1-2), and in so doing delivers detailed information that clearly marks him as someone who knows about his cancer. We can see that in and through the question produced, the doctor orients to the patient as someone who is an *established* patient with a history, who has already interacted with other health care professionals. The question attempts to 'get at' part of the patient history by inviting him to share something of what he has previously been told. And, as we shall see, patients respond to this request by recalling and reporting on part of their prior history.

Extract 4.3 (Case 1).

01	D:	what did Mr X say to you after the operation about	←1: Question
02		what he'd found	
03		(0.5)	
04	P:	.hhh H:e,er well we had <yeph> he said that	←2: Answer starts
05		he'd found- it- ORIGINALLY (0.5) um I thought	
06		I had (.) been cleared on the (0.5) ↓colon=	
07	Dr:	=right=	
09	Pt:	=um:: (0.5) ↑Mis:TER X then informed me after the	
10		operation that he had removed a tum↑our (.) and that	
11		it was on the co↑lon (1.0) and that I would have to	
12		come back here for (.) >↓further ↓treatment<=	
13	Dr:	=°okay°	
14		(5.0)	
15	Pt:	.hh we subsequently saw him last ↑Mon↑day (1.5)	
16		um: ((cough)) <he filled us in on a few more details I	
17		did ask about ↑stag↓ing> (.) er:: dukes T3 (.) um::	
18		(1.0) he's: said that (.) two of the lymph nodes HAd	
19		become (.) I think his words were (defe↓ctive)=	
20	Dr:	=right=	
21	Pt:	=<oh yeah> the SCAN- CT scan (1.0) um: I have the	
22		confirmation this morning (.) first of Feb=	
23	Dr:	=right o↑kay=	
24	Wife:	((aside))	
25	Dr:	(THER(h)E'S? ((laugh))	
26	Pt:	(that's right)	
27		(1.0)	
28	Pt:	Mr Cook did s:ay (.) last week um (0.5) he thought	
29		when operating he (.) could feel (.) a MAss:: (.)	
30		<over the liver>=	
31	Dr:	=right=	
32	Pt:	BUT (<in his words>) I don't know, I cannot be sure	
33		(I don't think Mr Cook's wrong) very, very many	
34		ti(h)mes ((laugh))= (...)	
35	Dr:	o(h)kay ((laugh))(.) how've you been since your	←3. Okay receipt
36		operation↑ have you made a good (.) recovery	plus another question
37		[from this o]peration↑	
38	Pt:	[I think so]	

In terms of turn taking organisation we can see that the doctor deploys an OQ, and this invites the patient to display his knowledge, "What did Mr X say to you after the operation about what he'd found" (←1.). The patient provides the first part of a multi-part answer (←2.), to which the doctor provides for continuation with the acknowledgement tokens "right" (7, 20, 31), "okay" (13) and "right okay" (23). The patient skilfully starts his answer by saying what *he* "ORGINALLY" thought. 'Originally' works as a chronological marker; he tells the doctor what he originally thought and forecasts talk about why the original thoughts no longer hold as relevant. Indeed, he skilfully elaborates his answer by narrating his journey along the cancer path by recalling the events in chronological order. In delivering his answer, the patient strictly adheres to the doctor's request to tell him what *Mr X said* through his lexical choice, "he said" (4), "he'd found" (5), "Mr X informed me" (9) and so on. Moreover, he reports what Mr X said *he found*, demonstrating clearly the local and contextual nature of talk (or more simply the close attention to a prior utterance to produce a next and procedurally relevant action).

In short, the patient orients to the 'project' of the question; "one party asks a question...the other party properly speaks, and properly offers an answer to the question..." (Sacks, 1992: Volume I, Part III, Spring 1966, LC2 (R): p264). More than that, we can see that this patient response displays 'specialist' knowledge. The patient responds to the doctor's request to tell him what the surgeon 'said he found' but his answer produces *his* history, which includes a sketch of the clinical journey followed, the tests and the results of those tests. On this occasion we can see that the doctor responds to the patient delivered information via the backwards-forwards particle 'okay'. That is, he contiguously acknowledges the patient's prior talk whilst moving forward to continue with history taking (←3.) (see Beach's discussion of the actions performed through the deployment of the 'okay' particle, 1993).

Let us loosely gloss what actions get performed in this lengthy sequence.

D delivered Q

↓

P delivered A (over 20 lines)

↓

D delivered Q

+ D produced response tokens, offering a continuation function, and display of understanding.

In terms of the information produced and offered by the patient, as in the sequences in *Chapter Three*, the patient recalls information shared previously and formulates the information in euphemistic terms, "found it", "staging", "problem valve", "mass", "lymph nodes" and "tumour". All are cancer implicative and the additional information proffered indicates a view of the patient's cancer journey. The following details are offered, and in this order.

a) Found 'it'
b) Operation
c) Tumour
d) Further treatment
e) Further diagnostic details, staging, lymph nodes
f) Investigative tests, scan
g) Mass over liver

Earlier on in the consultation, the doctor's questions about the patient's journey to the here and now solicited information from the patient about how his "small bowel" was "blocked". Here, by contrast, the solicited information marks the patient as a *patient who knows about his illness.* Still, as in *Chapter Three*, although cancer is implied, the lexical cancer is not uttered (Lutfey and Maynard, 1998). This is not to suggest that the absence of the word 'cancer' presents a problem; the patient clearly displays knowledge of his condition. The doctor's question is adequately attended to and the doctor moves to enquire how the patient has recovered since the operation. It is interesting to note again that frequently the term 'cancer' is not used straight off by the doctor during the history taking moments and, it seems to be the case that, these

questions serve a function in terms of (1) two 'strangers getting acquainted' and this generally involves (2) patients making the first mention of 'cancer'.

In terms of the production of the answer, once the patient has delivered the information about a 'mass over the liver', following a doctor delivered continuer 'right', he shifts the direction of talk to offer an 'inability account', "BUT (<in his words>) I don't know (.) I cannot be sure (I don't think Mr X is wrong) very, very many ti(h)mes ((laugh))=" (32-34). This account works to orient to the fact that this is 'reported speech'. The patient implicitly sets up a contrastive set of knowledges; that of *his-as-lay-patient* vs. the *expert-surgeon's* who is not "wrong very many times". Indeed, in my data corpus, in response to doctors' "perspective invitations" or OQs about what Mr X did or said, patients recurrently invoke a cautious approach to reporting on another's words. They skilfully inform doctors that the report is to be heard as 'a report'; that is, they inhabit the role of 'animator' of other 'authored' speech (Goffman, 1981[2]). Notwithstanding, patients can and do produce detailed information about their diagnosis, surgical intervention and, oftentimes, their prognostic outlook. In this sense, it might be possible to speculate that the inability accounts mark patient reports as cautious in regard to their relation to the knowledge / information being noted and not, necessarily, in regard to an inability to recall something about their cancer. We will come back to this point and develop it throughout the chapter.

Before viewing another fragment, we need to look in a little more detail at the type of information that a question like that posed above can solicit. In particular, from this OQ we can see that on-topic elaborations occur and may be informative in ways that stem beyond the patently *targeted information.* We have already touched upon the insights provided by Stivers and Heritage's (2001) case study of a primary care patient in the USA and how a patient may tender expansions to a doctor-produced question during history taking. The details of the different kinds of expansions are not germane at this point, the important point to keep in mind is that patient answers can be informative in terms of the 'project' of the question but may also proffer a glimpse into matters that are not so tightly bound to diagnostic, procedural and prognostic

[2] *Chapter Five* deals with the issue of 'footing' in more detail, with special reference to the action of doctors 'giving evidence' to support diagnostic embellishments and treatment disposals.

details that the doctors are seeking to establish. For example, in *Extract 4.3*, we also hear the following.

1. The patient was cleared first of all and had the difficult situation of then being told that was not in fact the case. That is, he was not 'clear' of cancer.
2. The patient has done a lot of reading and knows about such things as the Dukes Classification of bowel cancer.
3. Through his answer, the patient expresses the gradual / incremental nature of the journey: a) cleared, b) operation, c) tumour found, d) lymph node news, e) awaiting scan to be performed and f) possible mass over the liver.

In *Extract 4.4* (continued from *Extract 4.2*), during history taking the doctor asks the patient a question that again seeks information about what he was told after his operation (→1.). The patient provides a response (←2.), which further resonates with the comments made by Stivers and Heritage (2001).

Extract 4.4 (Case 2).

01	Dr:	↑what did the ↑surgeon say to you ↓after the operation	←1: Question
02	Pt:	he said that um: (.) he was ↑quite pleased with the way it	←2: Answer
03		had ↓go↑ne	
04		(.)	
05	Pt:	um: it was a (.) small tumour which <I ↑think> he said	
06		was about 2-4 centimetres um:: h::e (.) ↓didn't (have)	
07		any information <as to whether> at ↑THAT stage if it	
08		had got ↑THRough (the wall) I think at that stage he was	
09		waiting for the (.) ↓path report .hh but ↑he seemed quite	
10		pleased <he said we'll> ↑TAKe the right side off um:	
11		<sort of> (re-join you) and you should be working as normal	
12		(.)	
13	Pt:	↑s:o (.) .hhh that's how it was left at the time.	
14	Dr:	and h::↑ow've you been ↓physically ↑since the operation	←3: Question
15	Pt:	um: (0.5) <I think> pretty ↓good ((continues))	
16	Dr:	=o↓kay (...) < ↑now> in the ↑past have you had any other	
17		serious ↑illnesses, oper↓ations, anything like ↓that	

Following the doctor's invitation to report what he was told, "↑what did the ↑surgeon say to you ↓after the operation" (←1.), the patient begins his answer (←2.) and this continues over 12 lines. In his answer he demonstrates that he is *a person who knows about his cancer diagnosis*. Again, the patient strictly adheres to the 'project' of the question by delivering what he thinks he was told by Mr X. There is also a texture to the patient answer that again suggests epistemic caution, where he uses "I think" formulations (5, 8). His talk, like that of the patient in *Extract 4.3*, also involves some turbulence, with micro pausing and stretched 'ums', which in the case of both may indicate 'a process of consideration' of what to report next (Stivers and Heritage, 2001). In short, the patient works at *getting his story straight.*

As with *Extract 4.3,* the question solicits information that appertains to the patient's cancer and this includes:

a) Operation went well.
b) Tumour found.
c) Tumour size "2-4 centimetres".
d) Tumour location/spread "through the bowel wall".
e) Procedure for removal "re-join you".
f) Surgical outcome "working normally".

To gloss this even further, the patient produces information about diagnosis, procedures carried out and the outcome of the surgery. On this occasion, unlike *Extract 4.3*, the patient does not produce prognostic implicative information or raise the prospect of further treatment, i.e. chemotherapy. Rather, the patient displays an awareness of a diagnosis that is cancer implicative and reports on his exchange with the surgeon, which adequately attends to the project of the question. More than this, from this OQ, we can again see that the patient provides information that transcends the purely clinical:

1. He recalls the surgeon's thoughts on how well the operation had gone, "quite pleased". It is interesting to note that he produces this report twice, both at the start of his answer (2) and towards the end (9).

2. The patient also invokes the gradual / incremental nature of the journey: a) surgery, b) small tumour found, c) waiting for news on spread of tumour, d) pathology report pending and e) outcome of surgery means that he is functioning or working normally.

In addition to answering the doctor's question, the patient offers a clue as to a possible 'pre-occupation' or perspective on what he has been told. That is, the patient clearly has taken on board the surgeon's comment "quite pleased" and this may be important in terms of how the doctor addresses the task of delivering further information to the patient. Indeed, that the patient actually begins his answer turn with the report that the surgeon was pleased is important. This report is not relevant in terms of a surgeon who is 'happy with his own performance' as a surgeon, but rather the consequence of a pleased surgeon is relevant i.e. a good outcome of the surgery. To summarise the import of these observations, Stivers and Heritage state that such "additional material" can "indicate features of the patient's life-world which are, for the patient, variously matters of significance, concern or preoccupation" (2001: p 179).

Also similar to *Extract 4.3* is the doctor's lack of uptake on completion of the patient's knowledge/perspective display. Instead, with the sequence closing third, 'okay', he continues with the history taking (→3), using the power of the repeat 'rule' or the Q-A chain[3,4]. It is inescapably the case that the institutional mantle of the occasion is, in part, invoked by this Q-A-Q pattern[5]. Such a turn taking organisation has been described as, "prototypical of 'segmented' Q-A sequences" and one implication of such an organisation is that a doctor may treat patient talk as a response

[3] He holds off providing a response but, as we shall see, before commencing treatment talk, he deploys a knowledge summarising device or knowledge proposal based on the patient's displayed knowledge. We will come to this later.

[4] Sacks informed us about the basic rules of conversational sequencing in the case of two party talk. He stated thus: "One basic rule of two-party conversation concerns a pair of objects, questions and answers. It runs: If one party asks a questions, when the question is complete, the other party properly speaks, and properly offers an answer to the questions, and says no more than that...A second rule, and it's quite a fundamental one, because by reference to it the infinite character of a conversation can be seen is: A person who has asked a question can talk again; has, as we may put it, 'a reserved right to talk again', after the one to whom he has addressed the question speaks. And, in pursuing the reserved right, he can ask a question. I call this rule 'the chaining rule' and in combination with the first it provides for the occurrence of an indefinitely long conversation of the form Q, A, Q, A, Q, A...". Volume I, Part III, Spring 1966, LC 2, 1992: p264.

[5] Indeed, such extended question-answer sequences can sound interrogative in nature and are commonly associated with legal contexts (Atkinson, 1992: p208).

to a question "rather than as a narrative that itself requires a response" (Stivers and Heritage, 2001: p176).

Finally, in *Extract 4.5*, the doctor deploys the same question type seen in *Extracts 4.3* and *4.4* or, as Maynard calls it, the "perspective invitation" (1-4), and we can see a similar treatment of the patient produced answer.

Extract 4.5 (Case 3).

01	Dr:	CAN I ↑ASK YOU jus:t (.) in your own words	←1: Question
02		what you understand from what (.) <first of all> Dr	
03		↑X (.) told you (.) [an]d THen from w↑hat (.) Mr	
04		↓Y has sai- told you=	
05	Pt:	[(I-)] =um:: I think Dr X told me	←2: Answer
06		(.) more or less the same as Dr Y	
07		(1.0)	
08	Pt:	°yes um:° in that um: (.) well his- his words w↑ere	
09		it's not too big and it's not too s↑ma↑ll (.) an:d	
10		(1.0) hhhh well I'd a: I'm sort of er: led to believe	
11		it's like fifty ↑fif↓ty. I-I-I can (.) be c↑ured or (.) it	
12		depends on this ↑er: che↓mo	
13	Dr:	in the ↑PASt have you had ↑any (.) other serious	←3: Question
14		illnesses or operations <high blood pressure,	
15		diabetes, TB> or anything ↓°else°	
16	Pt:	°no°	
		... ((History Taking continues))	

In this fragment the doctor's question invites the patient to state what she understands from two other doctors. Again, this method of question asking invokes other structural resources and moments on the patient's journey. She responds, "=um:: I think Dr X told me (.) more or less the same as Dr Y" (5-6), which is followed by a (1.0) inter-turn gap. Although the patient answer could be possibly complete, the fact she has the go-ahead to answer a question combined with the silence she continues (e.g. Atkinson, 1992), in much the same way as the longer (5.0) silence in *Extract 4.3*. The patient's initial answer provides her view on the similarity of information shared with two healthcare professionals, but nothing of the content of the information shared is revealed.

During the continuation of her turn (8-12) she shows the doctor that she is a patient who knows about the cancer. Whilst she does not utter the lexical 'cancer' in particular, she invokes the cancer diagnosis, e.g. "it's not too big and it's not too s↑ma↑ll (.)" (9). She also displays some knowledge of the prognostic upshot, "I'm sort of er: led to believe it's like fifty ↑fif↓ty. I-I-I can (.) be c↑ured or" (10-11). This utterance (talk of cure) unequivocally reveals some patient ownership of their cancer status.

The odds of cure are produced with a notable amount of turbulence. As well as orienting to the consequential nature of the news being shared, this turbulence also possibly works to orient to her relationship to the displayed knowledge. That is, she is not the author but the animator of the prognostic relevant news. Hence, definite statements about medical matters or answers that invoke a level of certainty about medical issues do not hearably fall within her discursive jurisdiction.

Once her answer is hearably complete, the doctor again continues with history taking (←3.). He thus 'withholds' a response to the patient displayed knowledge. Again, the turn taking organisation in *Extracts 4.3*, *4.4* and *4.5* can be glossed as follows:

D produced Q

↓

P produced A

↓

D produced Q

On this occasion, in *Extract 4.5*, the move forward is not tied to the answer produced. The institutional mantle of the occasion is invoked in quite strong terms through this one action slot (←3.), where the doctor asks the un-prefaced question in third position. This could certainly be made into an accountable activity if this were another sort of occasion (Sacks, 1992).

4.3.1 A summary

In *Extracts 4.3* through *4.5*, patients are invited to display their knowledge by essentially recalling events that have occurred at other points on their illness paths. In

particular, they are encouraged to display information gleaned from prior interaction with their surgeon. The 'perspective invitation' works to solicit intricate deliveries of potentially 'delicate' matters. These 'displays' *authorize* doctors (and patients) to pursue the consultation agenda, and more strongly than at any earlier juncture during the course of history taking, cancer becomes a 'mentionable something'. The latter point is not inconsequential because we know these meetings are inescapably agenda based and work must get done in the short time together. Moreover, others have shown the disclosure of 'cancer' related information to be a tricky business, evidenced in the ways in which doctors and patients treat 'it' as interactionally delicate (e.g. Maynard, 2003; Lutfey and Maynard, 1998; Beach et al., 2005).

As in *Chapter Three*, here the tricky business of 'cancer talk' is undeniably made possible through the work that patients 'do'. Patients narrate their histories on request and in highly specialised ways. To summarise such deeply consequential information is a skilful accomplishment and reminds us of the inadequacy of conceiving of doctor-patient interaction as involving doctors *giving* and patients *receiving* information. Here, we see one example in which patients produce information that sets them up as lay-experts who are integral to the management of cancer information in the consultation.

In terms of the Q-A-Q format, this is basic 'machinery' identified some time ago (Sacks et al., 1974) and a series of studies have identified a similar pattern in other casual and institutional meetings. For example, Atkinson's (1992) work on courtroom talk tells us that more usually witnesses' answers are responded to by simply proceeding directly with a next un-prefaced question (p201), and here we see this format. These forms do vary in quite subtle ways, however, and this was demonstrated in Atkinson's examination of small claims courts in which he shows us that plaintiff's comments *are* met with receipt markers such as "certainly". He suggests that arbitrators' practice of acknowledging receipt before asking further questions helps to put plaintiffs at ease and provides an indication as to how the answers are heard; that the "just completed utterance was received and understood"

(p202)[6]. We can see this pattern in *Extract 4.3* where the 'okay' particle is produced[7,8].

The patterns seen in the previous extracts resonate with Atkinson's (1992) descriptions of how Q-A exchanges are achieved. Silence following a (possibly complete) patient turn, results in further patient-delivered information. However, unlike the case of small claims proceedings, doctors do not always receipt patient talk and may proceed in a more formal non-receipt pattern found in other more formal 'cross-examination' settings (Drew, 1992).

Let us summarise the question type reviewed so far.

Table 1: Open Questions/Perspective Display Invitations[9] during history taking

Question shape	Open question / display invitation
Example	"Can you tell me what Mr X said"

Given what we already know about medical meeting and, more particularly, history taking, finding a Q-A-Q pattern in these history-taking fragments is hardly astonishing. Notwithstanding, there is *still* much to be learnt about the forms these questions take, and how and when they are deployed. These questions, along with features of the so-called bad news meeting are integral 'parts' of the communicative project in cancer meetings. Maynard (1992) tells us that such question types are found in ordinary or non-institutional talk and he says the following about these:

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[6] Atkinson also tells us that plaintiffs provide elaborated answers when a yes / no will suffice. This was observable in *Chapter Three*, with the statement + tag formulations.

[7] The corpus is too small to be able to ascertain any significant meaning behind these subtle differences.

[8] Arbitrator silences before receipting also work to give the plaintiffs one last chance to complete or add to their turn. On completion arbitrators acknowledge, pause and then ask a next question. Unlike courtroom settings elaborated answers are not met with hostile responses (Atkinson, 1992: p206), but are in fact encouraged by the open question format and this is also the case for Atkinson's (1992) small claims court data. As Atkinson argues, receipting and being tolerant of non-minimal (i.e. other than what had been projected by the question) responses avoids disaffiliation.

[9] The use of the term 'perspective', as in Maynard's "Perspective Display Invitation/Series" (PDS), is somewhat inadequate. It risks misrepresenting what action doctors are precisely performing in these question turns. That is, they are not looking to solicit patient perspectives per se but rather are interested in ascertaining patient characterisations of what other health care practitioners have told them on previous occasions. These are quite different information seeking agendas and, although Maynard's PDS works to describe the question-answer sequences analysed here, it is important to bear in mind this important difference, whilst reading the following pages.

> In ordinary conversation, the perspective-display invitation and its reply operate like a pre-sequence and seem to have alternative trajectories. Sometimes, the asker follows a reply with his own report, or with further questions and then with his report. In this case, the third-turn report is akin to a "news announcement" (Button and Casey 1985), providing for at least some "receipt" of the report or possibly a "topicalizer" in the next turn; this topicalizer then occasions elaboration of the topic by the one who initiated the series. At other times, the reply to a perspective-display invitation *will be followed by further questions* or other topicalizers that permit the recipient to talk at length on some topic. The questioner, never announcing any independent information or perspective, appears to "interview" a recipient and provide for that person to do extended topical talk.
>
> 1992: p334-5.

Maynard's (1992) comments about 'ordinary conversation' resonate with the sequences reported above. That is, the doctor continues to "interview" the patient. In 'informing interviews' with parents of children with developmental difficulties Maynard also shows us that the information provided by a recipient to news or an answerer to a doctor question may be used by doctors to provide 'information as confirmation' of a patient's delivered perspective or information. He states thus:

> In the clinical environment, the relationship between the first two turns and the third-turn report in the perspective-display series appears more fixed or rigid than in conversation; only one of the alternative trajectories occurs. After asking parents for their view, clinicians unfailingly provide their assessment of the child.
>
> 1992: p335.

Here, in history taking, we have both trajectories in place, as described by Maynard (ibid.). That is: (I) third turn as question and (II) third turn as assessment, followed by doctor delivered information. So far only (I) has been examined. The latter of these two (II) is (generally) found later on in the history taking 'phase', when all information gathering is complete. There is, then, a noticeable (and systematic) differential treatment of patient produced information / perspectives and this generally seems to be related to the place in history taking[10].

[10] With the exception of one case in which the patient offers prognostic information of no cure *early* on in the consultation and the doctor responds with confirmation rather than a question.

4.3.2 Examining 'Open Questions': Patient answers and doctor responses during later history taking moments

Let us now examine a collection of type (II) questions, where we consider patient answers and third turn treatments of patient answers. In *Extract 4.6* below, the Q-A exchange is not repeated in the 'chained' A-P fashion that is characteristic of earlier moments in history taking. Rather, the patient's answer is followed by an assessment in the form of an agreement, "yes that's right" (→5.), an upgrade of the patient's utterance from "another growth" to "recurrence of cancer" and, finally, diagnostic ID.

Extract 4.6 (Case 4).

01	D:	°okay° .hhh and what was explained to you by the (.)	← 1: Question
02		surgeons <by Mr X's team and by Dr Y>	
03		(1.0)	
04	P:	what do you mean what was explained	
05	D:	what did they say to you about what they'd found when you	
06		came in	
07	P:	well they found there was another growth between the	← 2: Answer part one
08		kidneys mm hm yeah (.) and that's what stopped the kidneys	
09		from working	
10	D:	right (.)	
11	P:	and so (.) course I had to get them going again	← 3:
12	D:	°right°	
13	P:	but ah (.) Mr X said now look the thing is we can't cure ya	← 4:
14		but we can make things a lot more (.) °better for you°	
15	D:	right okay .hhh (.) what I would say is that (.) first of all yes	← 5:
16		that's right	
17	P:	yeah	
18	D:	when you came into the hospital	
19	P:	yeah	
20	D:	the problem was due to a recurrence[11] (.) of the cancer	
21	P:	yeah yeah	
22	D:	which was stopping the kidneys [working]	
23	P:	[yeah yeah]	

[11] I attempted to avoid recruiting people with a previous episode of cancer, but some patients in the corpus do in fact have a prior history. I do note when this is the case and, as already specified, many of these have been excluded when the concern is with history taking between to interlocutors who have not previously met.

In *Extract 4.6* the doctor's first pair-part of the question-answer adjacency pair is deployed when he asks, "...what was explained to you by the surgeons...?" (→1.). At line 4, the patient seeks clarification in next turn position, which marks the equivocal nature of what it is doctor wants to know[12]. OQs can produce possible difficulties for respondents in terms of where to start their response or 'story'. Indeed, insertions like this (or next turn other repair initiators, Drew, 1997) are common in research interviews, where interviewees may seek clarification from the interviewer of where they require them to begin their 'story' or narrative turn (see Kelly, 2003).

Returning to *Extract 4.6*, the doctor reformulates his first part in response to the patient's querying insertion, "... what did they say to you about what they'd found when you came in..." (5-6)[13]. In so doing he specifies much more closely what it is he wishes the patient to convey. The patient provides an answer (→2), "well they found there was another growth between the kidneys", which tightly orients to the doctor's search for 'what they said they'd found'. The doctor offers a response token "right" (10), which marks the information as heard and provides for continuation. Next, the patient continues her turn and elaborates (→3.) whilst the doctor provides "°right°" tokens, which again work to tell the patient that he is listening. At arrow 4, when the patient has said, "but ah (.) Mr X said now look the thing is we can't cure ya but we can make things a lot more (.) better for you", the doctor provides agreement in the form of a confirmatory evaluation of what the patient has said, "right okay .hhh (.) what I would say is that (.) first of all yes that's right" (→5.). In other words, in contrast to *Extracts 4.3-4.5,* the post Q-A slot here comprises a doctor-produced agreement. I will return to this fundamental point in a moment. For now, let us stay with *Extract 4.6.*

The patient's *answer part one* (→2.) comprises two parts, 'found a growth' and this was 'stopping the kidneys working'; this information is elliptical. She does not provide evidence of the (poor) prognostic information that the doctor presumably needs to have clear before he delivers further diagnostic information and the consequential treatment suggestions (not curative on this occasion). Nor, in fact, does she introduce the lexical cancer to her turn. Rather, she initially topicalises the

[12] Such insertions, as in Q[q-a]A, interrupt the Q-A pattern but do not disrupt it because the original Q is generally returned to rapidly.

[13] He continues to operate within what Maynard (2003) calls the "unmarked" frame. His question does not have a negative or positive assessment attached.

practical side of surgery, in particular the need to have kidneys that work. The doctor provides for continuation twice more until the patient provides the prognostic upshot of the information that she has displayed, i.e. that the cancer is not curable. Only then does the doctor produce his response, in the form of an agreement or confirmation of the 'factual fit' of the patient's informing. Together, doctor and patient establish the diagnosis, prognosis and later (not shown) the potential treatment plan.

As with all of these consultations, doctors could (speculatively) assume that patients know or 'own' their cancer diagnosis, because of their place on the cancer pathway; they have already had the so called 'bad news interview'. Rather than doing so, before moving to discuss the extent of the disease and treatment possibilities, doctors demonstrably seek to establish what patients have already gleaned from other moments. Again, let us gloss the information that the patient provides.

a) Growth
b) No prospect for cure
c) Can make things "more better"

Unlike *Extracts 4.3-4.5*, this sequence has the features of Maynard's (1992) perspective display series (PDS) (bearing in mind the limits of the term 'perspective'), including confirmation of the patient's 'perspective' / understanding (15-16) together with the use of that understanding to affirm and lead to what the doctor has to say (18, 20, 22). In this particular case, he upgrades "another growth" (patient's words) to "recurrence of cancer", and cancer is produced as a mentionable object. This fragment clearly provides an example of a different kind of Q-A sequence to that shown in *Table 1*.

Table 2: Open - type (II) questions

Question shape	Open question / display invitation	Evaluation
Example	"Can you tell me what Mr X said"	"Yes that's right, you had a recurrence of cancer" + further information

Doctor shifts from interviewing (IVF) to information delivery (IDF)

Rather than continue in the Q-A chain, the doctor makes something of the patient's response and shifts into information delivery. Again, to recap, Maynard (1992) has found similar question answer sequences in his work and contends that such a perspective display series can be viewed as a feature of institutional and casual conversational interaction where caution is required.

The perspective display involves the deliverer of news soliciting an opinion or perspective from the receiver of upcoming news. For example, in medical interactions concerned with the delivery and receipt of diagnostic or prognostic news, clinicians may ask recipients, usually the patient, to display their view or perspective of the situation before delivering their own view (as in *Extract 4.6* above).

The series typically comprises three parts:

1. Clinician's opinion-query, or perspective-display invitation;
2. Recipient's reply or assessment;
3. Clinician's report and assessment.

[Source: Maynard, 1992: p 333].

These three parts can take place over just three turns or over a number of turns, with small response tokens or insertion sequences (still topically tied to the perspective display/invitation). In addition, in contrast to the practice of providing an assessment in third turn position, as Maynard (1992) suggests, practitioners may follow with an acknowledgement ("okay") plus ID.

It must be remembered that these meetings are not first 'informing meetings' where so-called initial 'bad news' deliveries take place, when the diagnosis is arrived at for the first time. Most patients in the corpus have been through surgery and all have commenced an illness trajectory prior to the clinician and patient meeting. The encounters examined do, however, occasion further discussion of patient diagnoses and the consequential treatment recommendations. Doctors have clearly been shown to deploy the PDS in situations where caution is 'required'. Here, we see the PDS on an occasion where particularly consequential news about diagnosis and treatment will

be shared. The caution is not necessarily around the term 'cancer' but about establishing a common ground to enable further information to be tailored to the state of knowledge expressed by patients. Moreover, doctors take care to ensure their ID converges with ID by other doctors at another temporal moment.

Overall, when we compare *Extracts 4.3 – 4.5* with *Extract 4.6*, it is plain that the former of these extracts may be categorised as containing a foreshortened version of the perspective display series. Patients are invited to provide their perspective on what has been said or happened and patients do just that. Next, however, doctors keep with the task of history taking, and the 'series' is truncated. It seems that doctors tend only to provide confirmation or acknowledgement or correction when they are ready to do so. The third turn is different and, so it would seem, designedly so, according to the point on the history-taking trajectory and on what information has been shared.

The foreshortened perspective display invitation needs to be understood in terms of 'phasing' or activity types at different junctures of history taking. On the occasions in which the truncated perspective display is deployed, the majority occur during the earlier history taking, whereas the full perspective display series (with assessment / confirmation / agreement + ID) occur during the transition to treatment talk. That is, doctors hold off providing responses in the first instance because they are still orienting to the task of taking histories (to establish a mutual understanding of what has happened so far). Later, patient answers are used to confirm or reformulate and latterly proceed with ID[14]. The truncated display is a feature of the early history-taking phase of the consultation, where doctors stay "in the inquiry" (Jones, 2001).

A move out of that Q-A chain might threaten to overwhelm the agenda with patient initiated (off topic)-talk and the 'missing' assessment / evaluation needs to be understood in the light of 'phasing' and the related task orientation. Indeed, Stivers and Heritage (2001) note:

[14] An alternative way of co-implicating patients in upcoming information is shown in the Summative Knowledge Proposal, discussed in *Section 4.4*. Patient knowledge/perspectives are not invited, rather a shared knowledge of the cancer diagnosis is proposed.

> In ordinary conversation virtually any expansion... could serve as a launching pad for more talk. Comprehensive history taking, however, constitutes an environment in which this potential is most often curtailed. The need to progress the business of the interaction... and the primary mandate to orient to its medically relevant aspects, recurrently pose a dilemma for the doctor in responding to patient expansions. ...The doctor's failure to respond to expanded answers is not sequentially problematic, even though in ordinary conversation many of them might have been responded to. Thus narratives in the history-taking context can pit the normative pressure for response against the demands of the task in a much sharper way.
>
> p180.

We need to appreciate the functionality of this task orientation, rather than offer a straight-bat response of a critical ilk, which would involve disapproving of the constraining and asymmetrical nature of these medical meetings. Indeed, if we continue to focus on what the data tell us, we will see that patients themselves may do this perfectly well on their own, when they make visible and reportable the problematic nature of such a QAQ turn organisation.

To recap, although the deployment of the OQ / Perspective Invitation and the kind of information that it seeks to solicit suggests a sort of cautious epistemics in ensuring that patient's words are heard, this does not necessarily amount to doctors treating cancer as delicate. It is more about approaching what has been said previously to patients as delicate and ensuring subsequent news converges with that and, if not, doctors are forewarned and can elect to explain the hearable divergences or tailor their information so as to mollify the possible divergence. Doctors, in the here and now, demonstrably reveal an interactional preference for commencing from the 'right place' and they take care to make this so.

Let us view another perspective display series below to make clear the important difference of the third turn when compared with the earlier extracts. In *Extract 4.7*, following the doctor's question or "perspective invitation" (→1.), we see a patient-produced answer[15], which displays their knowledge of cancer and gets cancer mentioned for the first time in the consultation, "... all I know is they've taken a lump out

[15] The patient has an advanced stage cancer with lymph node involvement

with cancer" (→2.). The doctor provides for continuation (5) and the patient expands her answer (→3.).

Extract 4.7 (Case 5).

01	Dr:	can I just ask you what you understand (.) from Mr X	← 1: Question & agenda
02		(.) about what he fo↑und (.) and then I can (.) take	
03		things from there and explain where we go from h↓ere	
04	Pt:	all I know is they've taken a lump out with cancer=	← 2: Answer starts
05	Dr:	=right=	
06	Pt:	=and they took (.) eig↑ht lymph glands (.) five of	← 3:
07		which were cancerous	
08	Dr:	right	
09		(2.0)	
10	Dr:	and you've come to see ↑me (.) to think about (.)	← 4: Agenda statement
11		ch[emotherapy]	
12	Pt:	[about]chemotherapy	
13	Dr:	okay	
14	Pt:	( )	
15	Dr:	((cough)) if I can try and go through and explain	
16		things (.) a bit to you=	
17	Pt:	=um	
18	Dr:	and if there's anything that's un↓clear then (.) please	
19		come back (.) and ask (.) the questions o↓kay	
20		(1.0)	
21	Dr:	.hhh ((clicking of teeth)) <as ↑you> QUIte r↓ightly	←5: Agreement + ID.
22		say you've had (.) the mastectomy (.) and that's...	
23		((Continues))	

In *Extract 4.7,* we can see that the doctor solicits information from the patient and cancer gets mentioned quite quickly. The patient's display is followed by a doctor-produced evaluation and an upgrade of the patient's talk (←5.). There are a few, more detailed, points to be made.

At lines 1-3 the doctor asks the patient if he can ask a question and pre-announces his agenda or next activity, "and then I can (.) take things from there and explain where we go from h↓ere". At line 11, the doctor mentions the specifics of where "we can take things" by mentioning chemotherapy. Again at line 16, the doctor nicely moves into ID with the

pre-announcement, "if I can go through and explain things a bit to you" (15). He begins his ID with the "as you quite rightly say..." (←5.) and thus uses the patient produced information, whilst upgrading the situation with the reference to the mastectomy. In short, the OQ solicits information and this is used to move out of history taking towards ID. The way in which the doctor pre-announces his next action accounts for him (doing) being a *doctor-in-topical-control.* Significantly, in describing his next action, he makes (his broader view of) the course of the consultation clear for the patient.

In terms of the patient's response, she attends to the project of the question and produces information about the cancer diagnosis (lump with cancer; lymph nodes) and about the surgical findings following the operation and the lymph node harvest (6-7). This is a nice example of how the lexical cancer can be produced without any turbulence at all, in a straightforward or unvarnished manner. However, another kind of caution is present in regard to the knowledge being displayed and claimed.

Here in *Extract 4.7*, caution is evident as the patient prefaces her answer with the inability account, "all I know" (→2.). Her tag turns out to be unnecessary because the doctor treats her answer as offering a 'no problem' way to proceed. In short, the patient's response answers the doctor's query and makes possible (and relevant given the doctor's agenda statement) the provision of further detail by the doctor (not shown). Her next turn, "=and they took (.) eig↑ht lymph glands (.) five of which were cancerous" (6-7) displays a detailed level of knowledge, which renders her "all I know" even more interesting. We saw this kind of caution about knowledge claims in *Chapter Three*, whereby a doctor would display his knowledge of a patient's case by drawing on other structural resources, and invoked the limits to that knowledge because of its second hand nature. This course of action invited and secured patient clarification.

In the case of the patient's turn, by prefacing her turn with 'all I know' she treats the ownership of knowledge cautiously[16]. She claims knowledge on the subject, contiguous with portraying the limits of that knowledge. Indeed, the doctor has already (implicitly) categorised her knowledge as 'limited' in and through his chosen

[16] Indeed, we often see this *accounting for knowledge* work when patients respond to doctors' requests for information about what they know or about what Mr or Dr X has told them. For example, "all I know" (Case 5), "I can't remember" (Case 7), "Well Mr F hasn't told me very much" (Case 6).

formulation of his question, "can I ask you what you understand". That is, Atkinson's (1995) examination of how health professionals assemble patient cases away from the patient shows a diverse, yet on the whole professionalized and highly technical discourse, where knowledge is tested or oftentimes taken for granted.

As already suggested, Atkinson (1992) also shows us that in small-claims court hearings something as apparently trivial as pausing immediately after a witness-delivered comment provides space for the witness to augment their turns, before the arbitrator proceeds to acknowledge and pursue a different question. Silences can work to do this (see also *Extract 4.5*), but not unfailingly. Here, at line 10, we see that following the (2.0) silence[17] the patient does not speak up and so the doctor proceeds to produce the upshot of the patient's information (11). He does this via the addition particle 'and' which hearably ties his upshot formulation to his prior acknowledgement turn 'right' and to the patient's prior talk. The patient collaboratively completes the doctor's turn with her 'appended' utterance "about chemotherapy". Next, via the 'okay' particle the doctor acknowledges prior talk and forecasts topic transition (Beach, 1993).

For now, and crucially, we can see that the patient's knowledge is displayed, downplayed, agreed with and upgraded by the doctor, "hhh ((clicking of teeth)) <as ↑you> QUIte r↓ightly say you've <u>had</u> (.) the mastectomy (.) and that's re<u>moved</u> the can↑cer..." (←5). Next he topic shades from the diagnostic summary to his recommendations for adjuvant chemotherapy and the treatment talk commences (not shown)[18].

In *Extract 4.8,* again once the history taking is possibly complete, a further perspective display series is accomplished.

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[17] In this thesis, due to the lack of video data, I have deliberately avoided making too much of silences in talk. I am wary of doing so because the importance of gestural cues in interactions has been demonstrated and it would be too easy to 'over read' silences in talk or to read them in terms that are convenient to or supportive of the analysis. Obviously, this requests a sympathetic stance vis á vis the analysis provided, for I am certain others might choose to focus solely on the silences in talk, given their possible relevance. However, although this analysis draws on conversation analytic principles, it provides a more macro-sequential, step-wise view of the work that gets done along the trajectory of the consultation. This chosen focus dictates a less detailed analysis than some might prefer to perform or to read.

[18] When the doctor asks what Mr X found the patient curiously does not mention her mastectomy, but he seems to presuppose that mastectomy is understood.

Extract 4.8 (Case 6).

01	Dr:	CAN I ASK YOU (.) what you think, what you	← 1: Question
02		under↓stand from what you've been ↓told by Mr ↓X	
03	Pt:	well (.) Mr X hasn't told me um very much (.) but um	← 2: Answer starts
04		(0.5) the doctor came round the day before I was	
05		discharged ( ) and um told me that I had um	
06		<cancer of the liver>=	
07	Dr:	=right	
08		(0.5)	
09	Pt:	and (2.0) (I must admit to you) I was shocked but at	
10		the same time at least ( ) °	
11	Dr:	°okay° (.) if I can (.) g:o through things and try and	←3: Okay receipt + ID.
12		explain (.) <abit about> both what HAS happened (.)	
13		and what we (.) NEed to be PLANning to do (.) from	
14		no:w: < Okay?> (0.5) AT THE OPERATION which	
15		you've had- you had (.) a cancer of the bowel (.)	
16		which has been re↓moved (.) but at the TIME of the	
17		opera↓tion (.) it was noted that there'd been spread of	
18		the cancer to involve the ↓liver, alright? (.) so I'd say	
19		that there was the bowel cancer affecting the liver (.)	
20		rather than (.) cancer of the liver, right? <CANcer of	
21		the liver means it STARTED in the liver> =	
22	Pt:	=yes=	
23	Dr:	=but this is (.) CANcer from the bowel which has	
24		[spre]ad (.) TO the liver° (.) alright°	
25	Pt:	[( )]	
26		(2.0)	

Once history taking is accomplished, the doctor requests a display of understanding from the patient (→1.). She responds with an announcement that there was a "<cancer of the liver>" (→2.), but not before prefacing her turn with a qualifying statement that the doctor had not told her very much. She orients to the limits of her knowledge and produces possible grounds for that i.e. limited communication from Mr X[19]. Through her announcement, however, she demonstrates that she knows about her cancer. The

[19] By indicating that 'not much was said', the patient tells the doctor that she is a patient who perceives minimal information delivery. In today's 'information age', this skilfully works to invite / provide the doctor with a warrant to produce further information.

doctor holds off providing a response and after the (0.5) second inter turn gap (8) the patient expands on her turn to produce her *response* to the diagnosis again containing some pausing, which marks her report of emotion as potentially delicate, "and (2.0) (I must admit to you) I was shocked but at the same time at least" (9-10). This can be heard as a response to the doctor's "what you think" (1), as opposed to 'what do you understand'. The doctor's adjacent "okay" (11), again acknowledges prior talk and acts as a sequence closing in third position, which is followed by an agenda statement projecting ID, "if I can go through..." (11) (Beach, 1993). As with *Extract 4.7*, the doctor receipts the patient's *medical* knowledge display (11 onwards) and, to the exclusion of her comment about being shocked, moves forward to deliver further information[20].

Extract 4.8 shows how patient knowledge or understanding displays can lead to further tailored information delivery (11 onwards), in the lead up to and contextualising of talk about treatment (27 onwards, not shown). In this case, the patient's display has provided the doctor with information that suggests a slight misunderstanding; the patient has secondary liver cancer, and not primary liver cancer, which has important prognosis and treatment-relevant implications[21]. It also provides information on the patient's feelings about the diagnosis of cancer i.e. shock. And, as Stivers and Heritage (2001) suggest, it would not seem "profitable to treat [doctor's lack of response] as an instance of a broader pattern of 'insensitive' behaviour or of a generic resistance to the introduction of life-world topics" (p176). Indeed, they argue that patients actively and pre-emptively deal with and, therefore, curtail the need for a response to such displays of affect[22]. Indeed, here the patient detoxifies her own announcement of "shock" with her through produced "but at least...".

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[20] This relates to Sacks' (1992) comment about the difference between casual and institutional, specifically doctor-patient, interaction. He stated thus: "doctor-patient interaction is unusual because usually where there is occasion for sorrow or joy, news that will result in sorry or joy as a project will often be held off until after usual business is attended to. In casual conversation people will usually share the news straight off" (Volume II, Part VIII, Spring 1972, LC 6: p572).

[21] The patient had terminal bowel cancer, with liver metastases.

[22] *Downplays* of emotional matters are common in these kinds of interactions where biomedical matters appear to be pursued to the apparent dismissal of "person' issues" (Jones, 2001). This relates to a common knowledge on behalf of participants that emotional displays can interfere with professional matters.

Again, in *Extract 4.9* we see the deployment of a similar OQ, followed by a patient response and further doctor-delivered information. This is an interesting case because the patient orients to the difficulty of doing 'reported speech' in a number of ways, and this culminates in a patient request for some kind of independent assessment of her display. This fragment supports the idea that the cautious epistemics found in the talk might relate just as intimately to the act of doing 'reported speech', as it does to the topic of talk (that is, cancer).

Extract 4.9 (Case 7).

01	Dr:	RIGht, EXAMining you everything was ↓fine (.) alright?
02	Pt:	no tears or anything inside? (.) cos I really strained those first
03		few days when I got home [( )=
04	Dr:	[no,]=I think (.) EXAMining you
05		everything seems to be ↓okay (.) alright=
06	Pt:	=right
07	Dr:	could I ask you what (.) Mr A said to you then I can (.) take
08		things on (.) from there
09	Pt:	what do you mean, afterwards?
10	Dr:	YES, about what he found at the operation
11	Pt:	he found- <well I can't remember what he said about that> but
12		he said your (.) ODDS are (.) EVEN BETter than ( ).
13		but if I was him- <if he was me> he would want some chemo
14		just to make sure >that there is nothing left in there<=
15	Dr:	=okay
16	Pt:	but I don't know if that's (me being silly)
17	Dr:	((laugh)) t(h)hat not ((laugh))-
18	Pt:	IF YOU'D- if you'd seen me without me telling you (.) that
19		what would you say?
20	Dr:	<what I would> (.) s:ay is <exactly what I'm going to say now>
21		is try and go through (.) and explain to you FIRSTly- first of all,
22		<alittle bit about> BOwel cancer (.) and THen relate it to you as
23		to what I think we should be doing (.) in your situation (.)
24		alright?=
25	Pt:	=right.

Let us first deal with the actions initiated between lines 1-6. Following the doctor's post-examination announcement (1), the patient produces a response comprising two parts. The first produces a self-initiated query, "no tears or anything inside? (.)". The

second part of the patient turn provides the evidential basis for such a query, "'cos I really strained those first few days when I got home [( )=" (2). This is a skilful way of asking a question at a juncture of the consultation when, it is largely the case that the doctor asks and the patient answers. Indeed, that the patient provides grounds for his question orients to the shift he has made from *answerer-to-doctor-produced-questions* to *patient-questioner*. The account points to his ownership of the experience of having cancer, in particular the discomfort experienced on his return home from hospital (following surgery). The patient displays that he 'knows his own body' (Silverman, 1987) and implicit in this turn is a possible divergence between the doctor's "everything seems fine" vs. 'pain experienced by me as the patient'.

When patients produce these additional pieces of information they are adding "individual diary information" (Svennevig, 1999: p302). That is, this is information that the doctors cannot possibly know about, it cannot be counted as "mutual knowledge". When we consider the 'global' purpose of the meetings, such insertions of individual 'diary information' are central to the two strangers 'getting acquainted' or reaching a place where mutual understanding can be (more easily) assumed.

The patient is unsuccessful in terms of soliciting further information from the doctor, when in overlap the doctor produces a short response to the query "no" and proceeds to repeat his view that "after examining you everything seems okay" (4-5). This time the doctor lays claim to the conclusion of the examination with the "I think" formulation; he offers his *own* professional opinion following the examination.

Next, from line 7 the doctor produces an OQ that again seeks information about the patient's knowledge of "what has been found". In this fragment, the patient also requests an *other initiated repair* when he queries the information the doctor wishes to know (similar to *Extract 4.6*). The doctor responds by specifying more closely what he wishes the patient to share, "YES, about what he found at the operation" (10). Interestingly, the patient prefaces his turn by stating that he cannot remember what was said about the operation and, in the place of 'findings from the operation', he offers up at least some information on the odds of cure, which is topically related. The fact that the patient signals an inability to comment on his diagnostic details provides valuable information to the doctor. The reported inability to remember tells

the doctor that he may have to explicate the patient diagnosis in quite elementary terms compared with, for example, other patients who volunteer information about such issues as the Duke's Classification. The patient turn also works to orient to the limits of what he can say about what Mr X said, in a similar way to the previous extracts.

Once the patient produces his perspective on the treatment and his prospects of cure, he orients to his uncertainty about the facticity of what he knows, "but I don't know if that's (me being silly)" (unfortunately, the latter half of the patient turn is inaudible; indeed the tape quality was fairly poor overall), which could severally work to solicit a response on whether his claims are correct in the doctor's 'eyes'. The doctor's next turn (17) might be aimed at showing the patient that it is not him being 'silly', but either way his laughter works to dance around the patient's 'odds talk' and the patient's formulation that chemotherapy is not strictly necessary but will be used to "just to make sure". The patient's attempt to seek out the correctness or otherwise is followed by a more direct turn when he asks the doctor to tell him what he would have said had he not offered his own patient view, "IF YOU'D- if you'd seen me without me telling you (.) that what would you say?" (18-19). The doctor responds by offering an agenda and signals that his view has not altered what he, as the doctor, wishes to say. The doctor's turn tells the patient that he has thoughts on what "we" should be doing in his "situation". Interestingly, there is no real indication of the level of convergence or fit of the doctor's reasons for wishing to proceed with chemotherapy and the patient's thoughts on why it is necessary. Later in the consultation the doctor informs the patient that the use of chemotherapy is required because there is a 60-70% chance of recurrence if no more treatments are performed. This, then, has a slightly different and more serious complexion to the patient's view that chemotherapy will be administered to "just make sure". Thus, the limited response to patient talk at the history taking juncture might well reflect a steady, measured step-wise movement through the information sharing, which is required to interactionally realise a disposal for chemotherapy (or radiotherapy). Indeed, in *Chapter Five* we see that doctors generally (re)-produce patient diagnostic profiles in some detail, to confirm the consequential need for chemotherapy or radiotherapy.

This extract is remarkable on a number of levels. It provides a further example of a perspective-invitation and of how patients may signal their struggle to offer an answer that is germane to or adequately attends to the 'project' of the question. Equally, it shows how important these *knowledge* or *perspective checks* are with patients who have already had a diagnosis and/or surgery to remove a cancer. In short, just because of the place of a patient on their illness trajectory, health care practitioners cannot (and observably do not) assume what knowledge is 'owned' by patients. In a broader or distal sense this fragment further highlights the variability of what patients may or may not recall from previous meetings or may or may not have been told in previous meetings. Thus, the importance of the opening sequences and history taking moments is reinforced. They can be used, as here, to establish shared knowledge and thus a common ground, which helps to pave the way for further 'cancer and treatment' talk.

In terms of the patient's question, "IF YOU'D- if you'd seen me without me telling you (.) that what would you say?" (18-19), we see how patients may call doctors to account for the absence of an assessment of their answers. This is the only occasion in the corpus where a patient directly invites the doctor to produce their objective or unadulterated 'expert' perspective. This one example, nicely demonstrates the inadequacy of rigid or "one size fits all" formulations of doctor-patient communication (Arora, 2003). Indeed, the patient's request invokes the rules of everyday casual conversation. Often, in jokey fashion, interactants might say, "no you go first", or set up a reciprocal information sharing whereby, "I'll tell you if you tell me" or with more serious matters, when an assessment is 'missing', the speaker whose story / opinion has been offered might well ask, "well, what do you think?".

This extract also nicely invokes the concept of patient agency. Others have identified such self-initiated questions or insertions in 'second position' in clinical meetings (e.g. Peräkylä, 2002; Silverman, 1997; Stivers and Heritage, 2001; Drass, 1982). They signal certain flexibility in the turn taking *machinery* (a machinery which is not mechanical - perfunctory and involuntary - in the traditional sense).

Finally, one more example of the perspective display format is shown in *Extract 4.10.* This case is slightly unusual when set in the broader context of the data corpus because the doctor opens the consultation with the acknowledgement that the patient has got "rather mixed" or confused.

Extract 4.10 (Case 8).

01	Dr:	.hhhh (.) now I know you've got rather mixed in the last
02		[couple] of weeks.=
03	Pt:	[(oh yes]
04	W:	=yes
05		(0.5)
06	Dr:	if you could just start off (.) by telling me what you understand
07		so far and then I can totally explain from there=
08	Pt:	=well to start with after the operation I was ↑told I didn't need
09		chemotherapy ( ) any↑way ( )
10		when the operation was over they ↑told ↑me (.) that's what
11		they told me. but er: (.) now: I've heard that I've been (
12		) and I'm just interested to know why-why I need (.) it now
13		(1.0)
14	Dr:	o↓kay first of ↑all (.) I would say ↑that I do think you need to
15		have chemotherapy [treatment =
16	Pt:	[I ↑do =↓yes
17		(0.5)

In this final Extract, the doctor opens up the talk by stating the confusion experienced by the patient, ".hhhh (.) now I know you've got rather mixed in the last [couple] of weeks=" (1-2). This is met with agreement from the patient, "oh yes" and from the patient's wife (W:), "yes". Rather than clarifying the situation for the doctor straight off in terms of what exactly the confusion stems from, the patient completes his turn and the doctor again deploys the perspective invitation to solicit precisely what it is the patient understands 'so far', "if you could just start off (.) by telling me what you understand so far and then I can totally explain from there=" (6-7). In terms of broader theories of communication, especially the recommendations contained within much of the communications work conducted under the rubric of psycho-oncology, it is noteworthy that rather than assuming the reason for misunderstanding or confusion (which would generally be considered a 'bad practice'), here the doctor seeks clarification from the patient. We

see, therefore, that the perspective invitation works to establish a mutual understanding.

This example is particularly nice because the doctor's comment that he can "totally explain from there", once the patient's understanding is established, highlights one aim of perspective invitations. That is, doctors solicit information to establish what knowledge is shared and this in turn facilitates further ID. Here, once the patient articulates confusion over chemotherapy, the doctor strikes at the core topic of confusion or uncertainty by stating that chemotherapy is, in fact, required (14-15). Once his position on this, up until now, uncertain question is announced, the doctor proceeds to provide the evidential basis for such a treatment disposal, which has not yet (speculatively) been clear to the patient.

Here the power of the perspective invitation is demonstrated. An open question such as this solicits detailed information. Following the doctor's comment of confusion, and the patient and the wife's agreement turns, a short inter-turn gap ensues. Here the patient could have offered up the reason for confusion, but does not. It is possible that the patient might have withheld providing the reason for confusion because a question was not clearly implied through the doctor's turn and, as we go on to hear, the patient's confusion is connected to an occasion of conflicting information being provided by doctors, where chemotherapy was first said to not be required and then subsequently to be required. Thus, an implicit complaint is made through the patient's talk.

Let us summarise what we have established in this chapter so far.

4.3.3 A summary

In *Extracts 4.6* through to *4.10,* patient recall is tested and, in this way, patient knowledge is established through their *recall work.* These displays are solicited via doctor questions about what Mr X 'did', 'said' or 'found'. As with the questions in *Chapter Three* that served to establish how patients reached the here and now of the consultation, these information-sharing moments are achieved within the interview format (IVF) (Silverman, 1997). The doctor asks a question and the patient provides an answer, thus completing the adjacency-pair couplet of 'question – answer' (Q-A)[23].

Next, doctors produce a confirmation, reformulation or acknowledgement, and these are often prefaced with the 'okay' receipt, which less abruptly provides for a move from the interview format to information delivery, because of the acknowledging function of 'okay' (Beach, 1993). In short, displays are confirmed, embellished or corrected and information delivery pursued. Unlike the foreshortened perspective display where further questions are asked, these open questions share a similar function to those noted by Maynard (1992) in his recorded data of 'informing interviews'. We have also seen that in the case of slight misunderstanding of the diagnosis or diagnostic severity, doctors will also upgrade the display to incorporate a more accurate clinical description (Maynard, 1992: p340).

There are a number of other issues that are worthy of summary at this point. First, and importantly, cancer gets mentioned or intimated and, thus, becomes a 'mentionable'; "growth between the kidneys... can't cure ya" (*Extract 4.6*), "lump out with cancer" (*Extract 4.7*) and "cancer of the liver" (*Extract 4.8*)[24]. Second, the positioning of the perspective invitation, at the possible transition from history taking to diagnostic and treatment talk is relevant. Indeed, here we have a neat example of how inadequate analysis of turn-taking organisation is without analysing the sequential positioning of a turn within a broader trajectory. The full perspective display series tends to be produced at

[23] Sacks, among others, pointed out the moral obligation to provide an answer makes this a powerful device in terms of getting at what an answerer or, in this case, a patient knows.
[24] Patients do seem more likely to make the first mention of cancer when providing answers to the perspective invitations (full or truncated).

the tail end of history taking and this makes sequential sense; these moments are treated as opportunities to test and confirm diagnoses through patients' words and to proceed with the new 'phase' of the consultation. To provide more 'active' responses during the earlier history taking moments could (speculatively) diminish doctors' opportunities to proceed with the 'agenda' in such a stepwise fashion, without *off-topic* shifts.

The foreshortened or truncated perspective display permits and seems to be about the pursuit of history taking and the majority of patients collaborate in the history taking exercise. Such non-receipt or minimal receipt could cause problems in casual conversation, as it can appear to be (overly-) interrogative. In rare circumstances (in my data corpus), patients will make the lack of a doctor-produced assessment into an accountable matter. We saw the rare example of this in *Extract 4.9*; "IF YOU'D, if you'd seen me without me telling you (.) that what would you say?". Overall, however, patients and doctors continue along a convergent route, with or without 'active' doctor receipt[25]. Furthermore, for doctors to provide an assessment could be viewed as patronising by patients. These kinds of "yes that is right" or compliment sequences are most common in pedagogic environments (Mehan, 1981; Drew and Heritage, 1992). By refraining from that type of institutionalised format the patient is attributed 'theoretic capacity' (Silverman, 1987) or is constructed as someone who *is likely to know* and hence someone who does not need to be told they know.

When patients answer the questions offered, an interesting cautious epistemics is hearable. The transfer that patients are invited to make, from *lay patient* to *expert narrator* of a surgeon or doctor's words can pose a potentially thorny job for patients. Indeed, the way in which doctors ask this of patients indicates an orientation to a potential involvedness (i.e. a doctor-to-doctor request for knowledge or a perspective is likely to be phrased differently, Atkinson, 1995). As well as the technical intricacies entailed with such reports and the deeply consequential nature of the information

[25] When doctors do not produce an assessment, to suggest something is 'missing' (Jones, 2001) suggests a lack or deficit and this evolves out of the comparison of institutional talk and ordinary conversation and belies the task-oriented nature of institutional meetings such as these and the possibility for important visual cues and engagement work, for example (see ten Have, 2001; Heath, 1986).

being reported for the patients who have to find the words, the moral obligation to report Dr X's words accurately and without criticism is also strong.
We saw how patients attend to this in the phrasing of their displays, which orients to them as non-expert tellings. 'Reported speech' (Wooffit, 1992) of this kind can demonstrably lead to the downplaying of knowledge, perturbed speech, and self-effacing comments which all subtly seek assessment of the correctness of displays (*Extracts 4.9* and *4.8*). We see that these inability accounts or uncertainty markers about how to report and what to report turn out to be unnecessary. Patients display 'expertise' and may also skilfully weave 'life-world' material into their turns. Moreover, even when not technically 'accurate' we see that all perspective displays involve informing work that offers information beyond the project of the questions.

It is clear that 'specialist' meetings involve 'specialist' patients and not just 'specialist' health care practitioners. This expertise facilitates doctors in their pursuit of the institutionally ascribed tasks of delivering further diagnostic detail and sharing their treatment recommendations.

In more general terms, in *Extracts 4.3 – 4.10* we witness a form of *teamwork-in-action* where knowledge is cautiously requested and displayed. The deployment of the perspective display invitations suggests an orientation by doctors to an obligation (as a member of the category 'doctor' and all that is tied to that role) to protect patients from the discussion of unprepared subjects and in turn avoids the category type of *insensitive-doctor*. This is a form of accountability and intersubjectivity work before getting on with the *business at hand*. Moreover, in doing things this way doctors make their own task easier. They nest their information / news / treatment disposal in an environment that seems ripe for such deliveries.

Here, the perspective display series and foreshortened perspective display seem to be present as preludes to either: (1) diagnostic summaries and then on to treatment talk or (2) further history taking, rather than necessarily a 'prelude' to diagnostic news (Maynard, 1992: p.351). Sometimes this prelude is insufficient to solicit a specific mention of the lexical item cancer, whilst at other times cancer will be mentioned directly. Either way, these sequences occasion cancer implicative talk.

A core omni-present function of history taking has been documented in this chapter and the methods used described. Getting acquainted and getting to know what each other knows is patently at the heart of history taking. In similar vein, Sacks (1992) pointed out some time ago that, in casual conversation, orientation to co-participants is pervasive. As Sacks told us, one means of discovering what someone knows is to ascertain when you last spoke. During these first outpatient oncology treatment meetings, a similar pattern emerges; whereby doctors establish (1) that patients have talked with other doctors and in so doing they establish (2) what patients recall from previous meetings *with other doctors*. What patients know is determined (at least in terms of the project of the questions asked) and patient and doctor get acquainted on this level. Doctors and patients observably 'find' each other to "find which things to tell which person" (Sacks, 1992).

Finally, I want to discuss briefly a summarising device used in these meetings, which can (generally) be found immediately prior to diagnostic embellishment, during the pre-closing moments of history taking as with the PDS. Here, I classify this target phenomenon as an inter-subjectivity marker or *Summative Knowledge Proposal*. It is used in combination with and in isolation from the open question types discussed in *Chapter Three* and this chapter (*Four*). They serve a similar function to the perspective display series when doctors implicate patients in a shared knowledge and this acts as a prelude to and 'way in' to ID, in a ripe and 'shared' environment.

4.4 Summative Knowledge Proposals: "Okay, as you know you've had a cancer"[26]

The proposal of knowledge generally occurs directly before diagnoses are embellished and treatment is discussed. Usually, therefore, these summative proposals, simultaneously propose what may have been established during history taking and work to shift the talk forward to other matters. This particular approach to moving forward was routinely in place at both hospitals. The consultant at H2 tended to use this method of summarising as a topic-shifting device in isolation. Therefore, in providing this section, I provide a reflection of the different ways in which doctors may move towards diagnostic and treatment talk. The consultant at H1 used it in combination with the truncated or foreshortened perspective display.

Extract 4.11 is taken from a consultation with a 59-year-old woman in which cancer of the bowel is discussed. Following the doctor's report that 'everything seems fine' after the physical examination, he proceeds to summarise what has happened since surgery.

Extract 4.11 (Case 9).

01	Dr:	what I'd ↑<u>like</u> to do is first of all go over (.) what happened	←Agenda statement
02		at the opera↓tion	
03	Pt:	yeah okay=	
04	Dr:	=and <u>then</u> ↑explain (.) what we need to do next=	
05	Pt:	=right=	
06	Dr:	=and where we go from here=	
07	Pt:	=right=	
08		(0.4)	
09	Dr:	as I think you (1.0) <u>understa::ndt</u> (1.0) at (.) the	← 1: Knowledge proposal
10		operation a cancer of the bowel	
11	Pt:	yes=	← 2: Receipt

[26] This is the way in which the doctor at H2 often established or rather invoked mutual understanding / intersubjectivity regarding knowledge held. The PDS is a strategy used by the doctor at H1 (and H3, from the MRC funding, which is regrettably not a data set that were fully available at the time of writing). Therefore, in providing this section, I provide a reflection of the different ways in which 'oncology talk' can be, and is, done.

12 Dr: =was found (.) and that seems to have been completely

13 removed

14 Pt: yes

In *Extract 4.11,* the doctor first offers the agenda of recapping what happened at the operation (1-2) to which the patient responds in the affirmative "yeah okay" (3). The doctor explains that he would then like to link what happened to what needs to happen next (4), which (implicitly) forecasts the talk about chemotherapy. After this agenda statement, the doctor proposes that the patient understands that a cancer was found during the operation, "as I think you (1.0) understa::ndt (1.0)" (→1), to which the patient responds with the agreement, "yes" (→2). In a similar way to the checking in the early history taking, the doctor's proposal of knowledge solicits patient confirmation. This time it is their knowledge of a cancer diagnosis that is confirmed (not the journey to the here and now). The silences (inter-turn gap on line 8; intra-turn pause on line 9) mark the doctor's summative proposal as cautious.

Prior to this proposal, the word cancer had not been mentioned during the course of the consultation. The doctor had deployed the truncated perspective display device during the earlier history taking moments, but the patient responded elliptically by stating, "they said they'd taken *it* all away" (my emphasis). The doctor provided for continuation to which the patient responded, "they've had a good look around and they couldn't find anything out of place", at which point the doctor continued with history taking.

We have already seen in the previous section that sometimes the lexical item cancer will not be specifically mentioned during these history taking moments. Conversely, patients will, in a similar way to doctors prior to the first mention of cancer by the patient, use euphemistic descriptors or litotes such as, "it", "something" or "thing" and in so doing manage to talk about cancer in a 'roundabout' fashion (see Lutfey and Maynard, 1998). Such caution, in general terms, is not a new finding, but the presence of such interactional caution in the data corpus used for the purposes of this thesis contributes to a growing body of work. Moreover, the diverse ways in which 'caution' is accomplished, jointly, expands our knowledge of caution in its many forms. This ultimately contributes to an increasing ability to make claims in regard to

the generalisability of certain phenomenon, a meaningful outcome, if results such as these are to be taken seriously by those practising in the medical world (Drew, 2001). Again, to remind us, this talk paves the way for the pursuance of the 'main' or global agenda. In the case of *Extract 4.11* diagnosis is embellished and chemotherapy is discussed.

In *Extract 4.12*, the retrospective summarising of events and patient confirmation of those events is again achieved through the deployment of the summative knowledge proposal. Immediately prior to this fragment the doctor had conducted the examination and before that, the patient mentioned cancer via the truncated or foreshortened perspective display.

Extract 4.12 (Case 10).

01	Dr:	NOW (1.0) what all of that means (0.2) is that (.)	←1: Knowledge proposal
02		yo- you >as you know< you had a cancer of the	
03		bowel=	
04	Pt:	=°mmm°=	← 2:
05	Dr:	=which has been removed=	← 3: Elaboration on proposal
06	Pt:	=(yes)	← 4:

In *Extract 4.12* the doctor states, "...yo-you>as you know< you had a cancer of the bowel" (→1.) and in so doing he attempts to co-implicate the patient in the knowledge that a cancer was found, ">as you know<". The use of ">as you know<" works to downgrade the news from *something-the-patient-might-not-know* to *something-the-patient-already-knows*. An already established *partnership-of-knowledge* is proposed (presupposed) and confirmed. This common ground is reflexively created and reinforced through the patient's latched response token (→2.) "mmm", and early agreement "yes" (→4.). By delivering confirmation of the doctor's knowledge proposal in a simple, straightforward and unvarnished manner the patient aligns himself with the doctor's version of what he, the patient, knows.

The doctor's use of "as you know" is dissimilar to his use of "as I think you know" in *Extract 4.11*. *As you know* works to 'give credit where credit is due'; the patient had demonstrated their 'cancer' knowledge through earlier *display work* and the doctor displays confidence that the patient knows about the cancer. By contrast, the *as I*

think you know marks the proposal as tentative. It invokes caution about precisely what is or is not known and hence invites and allows for confirmation[27].

As well as indicating differing degrees of caution, these moments illustrate a respect over the rights of 'ownership' of knowledge, as displayed with the doctor's use of "as I think you know" (*Extract 4.11*). The doctor's uncertainty (as evoked by "as I think") functions to state cautiously who has the rightful 'ownership' of the knowledge or perspective that is being noted. This knowledge being proposed is intimately tied to the experiences of another (Peräkylä, 1995; Peräkylä and Silverman, 1991; Sacks 1992[28]).

The proposal of knowledge of cancer is consistently deployed at the end of history taking and the commencement of diagnostic and treatment talk in one of two ways. First, it is deployed and appears to offer an additional summary of what has been established earlier in the consultation (explicitly or implicitly). Second, it also offers an alternative strategy and is used, as already stated, most often by the doctor at H2, whereby he proposes that both are on the 'same page' (or have established a common ground) and, consequentially, that there is a 'ripe' environment to continue. In isolation it may appear to be a less cautious approach because patient views or understandings are not solicited in their own words[29]. Notwithstanding, it is used to summarise what has gone before in the consultation (before moving on to treatment) or is deployed in consultations where the doctor and patient have met previously (and cancer has been established as a mentionable object).

In *Extract 4.13,* we can see an example of a different kind of format where history taking is not deemed to be necessary (at H2), because a history has been provided

[27] Generally, I think these 'as you knows' may be about doctors orienting to the fact that a 'realisation' of cancer can take time. The as you know / I think you know is a way of marking a sensitivity to the upcoming announcements and represents an attempt to couch further ID in terms that suggest an 'open awareness' of the cancer. This is not, therefore, about sensitivity to cancer per se, but to the patient and their realisation or 'ownership' of the cancer diagnosis.

[28] See Sacks for a discussion of storytelling and 'Entitlement to experience'. Volume II, Part IV, Spring 1970, LC4, 1992: pp242-248.

[29] Inter-turn pausing does suggest some caution however. Perhaps this caution is related to the use of a more direct device for establishing what is known, before continuing to discuss the treatment implications of that which is known.

through the notes and, crucially, the patient and doctor have met on a previous occasion. Here the knowledge proposal "as you know" (5) is deployed.

Extract 4.13 (Case 11).

01	Dr:	so ah: (.) <I wanted to see ↑you> (.) not just to record what we are	←1: Agenda
02		d(h)oing ((laugh)) (.) but I wanted to explain to you wh-wh-what- in	
03		<alittle more detail> what the ↓plan is. o↑kay	
04		(.)	
05	Dr:	umm: Mr X <**as you know**> >took that< cancerous lump out of the	←2: Knowledge
06		↓ton↑gue (.) um: ↑HOPE↓fully he's removed all the cancer there is (.) and	proposal
07		(.) it wouldn't ↑come back but (.) cancer being ↓cancer one can never be	
08		sure=	
09	Pt:	=°no°=	

Here, in *Extract 4.13*, following the agenda statement the consultant states, "umm: Mr X **<as you know>** >took that< cancerous lump out of the ↓ton↑gue (.)..." (←2.). The 'as you know' component is again deployed (the 'I think' is absent, which seemingly displays less epistemic caution). It is only at line 9 when the patient responds with a "no", which works to acknowledge the doctor's talk about the general nature of cancer, that he proceeds to discuss the possibility of spread if the cancer is not treated further with radiation treatment (10-17) (not shown). The 'as you know' works as an inter-subjective appeal, where the doctor appeals to a common ground.

In this consultation, cancer has not been previously mentioned and the proposal is produced much earlier than in the H1 consultations and without additional devices. On this occasion, the patient and doctor have met, but even when this is not the case the consultations at H2 tend to not involve extensive history taking and the business of ensuring the patient and doctor are 'on the same page' seem to commence in more 'direct' fashion. Further, the nature of the cancer (head and neck) means that examinations are less marked (no undressing involved) and the transition through the different consultation 'phases' and associated tasks tend to be speedier.

Following *Extract 4.13*, as with the other extracts, the doctor works to embellish the cancer diagnosis in order to state the relevance and appropriateness of the adjuvant radiotherapy. The information is tailored by drawing on other structural resources,

such as the patient's file and multi-disciplinary team meetings. However, it is less obviously tailored in the *here-and-now* of the consultation than in the previous fragments when patients' versions are solicited in their own words. When taken in isolation, without knowledge of what has preceded this inter-subjectivity marker or summative device, the proposal seems blunt and it can result in 'rush throughs', where patient responses seem quite unimportant in shaping the doctor's next turns.

Table 3: The summative proposal that cancer is known

Question shape	Proposal that cancer is known with varying levels of caution	
Example	"*As you know* you had a cancer of the bowel"	"*As I think you know* you had a cancer of the bowel"

In *Extracts 4.11-4.13*, the doctor states the cancer diagnosis by using a knowledge proposal formulation. The normal series of turns involve the proposal (sometimes preceded by an agenda statement) of a shared knowledge that cancer is the topic of conversation (e.g. *Extract 4.12*) followed by confirmation that the patient is 'on message' that there was indeed a cancer (e.g. *Extract 4.13*), followed by the third part which contains the shift forwards to diagnostic embellishment and the treatment implications in light of the cancer; usually forecasted in the doctor's previous turn. In short, the knowledge proposal works to (1) gain alignment with the knowledge proposed and (2) move on to other matters, which will involve specifying in further detail the cancer diagnosis and the reason for or against chemotherapy or radiotherapy.

Consider *Extracts 4.14, 4.15, 4.16, 4.17* and *4.18*.

Extract 4.14 (Case 12).

01	Dr:	>and< (.) what-(.) what the pathologist has ↑told us is that (.)
02		**<well> we ↑knew** there was a small cancer in the ↓bre↑[ast
03	Pt:	[yes
04	Dr:	which is- (.) it was (.) picked up at the scree↑ning
05		[↑apparently ( )]
06	Pt:	[that's ↑ri↑ght and I had] n↑o idea=
07	Dr:	=<I was [gonna say> it was-] it was
08	Pt:	[couldn't ↑feel ↓it]=
09	Dr:	=↑VERY small=
10	Pt:	=um
11	Dr:	you certainly↑wouldn't have found this one=
12	Pt:	=n↑o:=

Here in *Extract 4.14,* again with H2, the "we knew" serves a similar function to 'as you know'. Who the 'we' are in this situation clearly remains unspecified, but the patient hearably treats this as including him in that category description when he provides a 'yes' response in overlap. Again, in *Extract 4.15*, we see the deployment of a similar proposal that knowledge of the cancer is *shared.*

Extract 4.15 (Case 13).

01	Dr:	.hhh (.) and **I think you are awar↑e** (0.2) when you had this
02		operation (.) a cancer of the (.) bowel (.) >was found<
03	Pt:	agreed
04	Dr:	.hh AND (0.1) when you ↑have an operation like this. what
05		hap↑pens is that you take away a section of the bowel (.)
06		together with lymph nodes (.) °al↑right°
07	Pt:	yes

Extract 4.15, provides a clear example of how a statement (similar to *Chapter Three*) need not be obviously query intoned to solicit a response from a patient; it may still be heard as an appeal for agreement / confirmation. The patient is, as Sacks (1992) told us, attending to the doctor talk and as a recipient to that talk he provides a procedurally relevant next action. The patient's "agreed" tells the doctor in quite strong terms that he is aware of the 'cancer of the bowel'. Once the common ground is

established, the doctor moves forward to provide more detail about the patient's diagnosis.

In *Extract 4.16*, the doctor again offers the proposal of a shared knowledge and the patient's single utterance in overlap, "ductile", signals that she is 'mind on' with the doctor's summary.

Extract 4.16 (Case 14).

01	Dr:	now if I can (.) go over what was found (.) and then (.) take
02		things from there (.) for you. al↑right (.) <**as you know**> there
03		was a (.) cancer (.) it was a (0.5) <what was called a> (.) a (
04		[a ductile)
05	Pt:	[a ductile ( )
06	Dr:	yes okay
07		(1.0)
08	Dr:	.hhh THe s↑ize of it (.) <I think it was> dif↑ficult to (.) measure
09		it exactly. (.) but they (.) reckon it was about 70 millimetres=
10	Pt:	=right=

Again, the doctor proceeds to produce more information following the initial proposal that cancer knowledge is *owned.* We see a similar pattern in *4.17* and *4.18.*

Extract 4.17 (Case 2).

01	Dr:	°oka::y° (.) .hh (.) **as I ↑think you (.) ↓kno::↑w** from the
02		conversation you had a cancer (.) of the bow::el:↓
03	Pt:	°yes°
04	Dr:	which has been removed.
05	Pt:	°yes°

Extract 4.18 (Case 15).

01	Dr	↑ANYway ↓mam (.) you're here to↓da↑(hh)y
02		(.) 'cos you've had a mastecto↓my ↓a (.) <couple
03		of> ↑weeks a↓G↑O
04	Pt	yes
05	Dr	um: (.) >**and °as you ↓know°**< it was a (.) cancer in
06	Pt	yes

Generally doctors' proposals that knowledge of cancer is a shared knowledge is met with agreement in the form of 'yes' or 'agreed'. In short, this final presupposition acts as a summarising device and it works to implicate the patient in a shared knowledge of cancer. This in turn paves the way for further information delivery about the cancer and its treatment. The proposal serves a similar (albeit shorthand) function as the perspective display series in the sense that a common ground is established and the doctors provide further information based on the 'agreed' (rather than 'displayed') shared knowledge; *implied* through the proposal and made *explicit* through the perspective display.

4.4.1 A summary

The knowledge proposal is a solution to the particular needs of these interactional episodes and that is to shift to diagnostic deliveries and treatment talk, co-operatively. As we have seen, at the point of their deployment (i.e. possible closing of history taking and transition to diagnostic embellishment and treatment talk), doctors have usually done some work around trying to gauge patient knowledge of their cancer diagnosis, and it is hearably assumed, even where cancer has not been directly stated, that the clueing by patient and doctor throughout the history taking makes the proposal acceptable. 'As you know' is a presupposition and acts as a mechanism that allows two people to talk in a way that suggests a "common ground". This does, however, leave open the possibility that doctors might end up presupposing a common ground that is more than they "actually have" (see Svennevig, 1999: p314).

The use of a perspectival comment such as, "as I think you (1.0) understand", shows that the doctor is attending to patient knowledge and the ownership of experience and knowledge (that is, it is the patient that has travelled the journey, in much the same way as the patient cautiously states what Mr X 'said' or 'did'). The "I think" component works to say *I-think-but-you-might-like-to-confirm-that-for-me*. It also provides an opportunity for the patient to request more information in the sense that the doctor's "I think" leaves it open for the patient to say *no-I-do-not-know-but-would-you-tell-me* or to say nothing at all. Having said that however, disconfirming

the proposal is not an equivalent action to confirming. Such 'dispreferred'[30] moves are difficult to make, especially when situated as a recipient to a proposal from an *expert-doctor*.

The absence of the "I think" component makes the proposal less of an invitation for patient agreement, but a statement which is pro forma in style and permits continuation with or without explicit confirmation. Having said that, there were no occasions when confirmation was not provided so it is difficult to trace the consequences of a lack of receipt or a dispreferred action of 'no I don't know'.

At H1, the build towards the *Summative Knowledge Proposal* is notable; foreshortened perspective display, perspective display series, and / or euphemistic descriptors are all deployed in an effort to gain alignment to the cancer talk and to get at patient knowledge before shifting to the diagnostic and treatment talk. On occasions when the doctor at H2 deploys just the proposal, the outcome seems to be the same: (1) knowledge is confirmed and (2) the agenda is pursued. However, although the outcome may be the same in terms of the 'successful' pursuit of the institutionally ascribed task of discussing adjuvant treatment, the knowledge proposal or summative strategy does not solicit patient knowledge or understanding of their cancer or other what others have told them about their cancer in any more than a confirmatory way. Patients 'opt in' to the proposed knowledge and doctors rely on 'local cleansing', when the patient might say 'no I do not know or understand' (see Sacks, 1992).

[30] This does not refer to a psychological notion of preference, but to the sequential organisation / turn design. The 'preference system' encourages solidary actions and the forestalment or minimisation of potentially disruptive actions (see Heritage, 1984: p276).

4.4 Conclusion for Chapter Three and Four: History Taking as Interaction

In *Chapter Four*, we have seen a continued and conjoint effort by doctor and patient to establish a common ground in relation to what each other knows about the cancer diagnosis. We have considered some of the sequential resources 'unacquainted' (and, less so, acquainted) 'interlocutors' (see Svennevig, 1999) use in order to share information, to introduce (potentially delicate)-topics and to make talk about cancer possible. Overall, during both Chapters on history taking (*Chapter Three* and *Four*) we have seen how doctors seek to solicit patient involvement in such a way as to demonstrate that they hearably 'own' their diagnoses based on their journey to the here and now and on what previous doctors have told them.

As stated, a recent study conducted in Japan (Phungrassami et al., 2003) showed that the mere fact of undergoing radiotherapy treatment did not ensure that all patients 'knew' or spoke in terms that indicated them knowing of their cancer diagnosis. The practices described in the foregoing chapters show how doctors and patients bridge the potential schism between their awareness of what has happened. These practices also diminish the risk of doctors producing information that is at odds with the information garnered by patients from other doctors along the trajectory. The interactional achievement of 'mutual understanding' that cancer is the topic of conversation sounds unremarkable, but it is this that largely enables the broader institutionally ascribed agenda to be upheld (affably), which is pivotal to the broader task of organising and managing patient care. They can move from what has happened to what will happen next.

During early history taking in *Chapter Three* doctors orient to establishing a "common ground" in terms of how patients came to be diagnosed and reached the here-and-now of the consultation. The open interrogatives, 'tell me how this started', are routinely deployed straight after the opening sequences when the first move to business is made. Primarily, these open interrogatives act as a 'way in' to history taking. Equally, we saw that the closed interrogatives (statement proposing the

journey to diagnosis + query tag) may feature. These questions result in patient confirmation, disconfirmation, correction or full(-er) narrative explanation of their journey to the *here and now* of the consultation.

As already noted, there is a cautious epistemics to the work accomplished during these early history taking moments and this is hearable on a few levels. It is also accomplished in a number of ways, through lexical choice, turn design and sequence organisation. Drew and Heritage (1992) pointed out some time ago that, 'cautiousness appears to be a feature of institutional talk' whereby participants in institutional interactions "design their talk so as to maintain a cautiousness, or even a position of neutrality with respect to their co-participants" (p47). We can see that cautiousness is enacted through the doctors' demonstrable need to establish that there is a 'common ground' before proceeding with history taking and, later, diagnostic and treatment talk. Second, the lexical choice during these early information-sharing moments exhibits a measured approach in terms of the use of the word 'cancer'. Instead, rhetorical forms or litotes, and euphemistic descriptors are used (Bergmann, 1992). Third, doctor claims about patient knowledge and patient reports of other health care professionals' informings are also performed cautiously. Both parties skilfully produce information, whilst simultaneously displaying the second hand or derived nature of that knowledge[31]. In their participation, doctors and patients attend to the moral universe and evoke knowledgeability in line with their (distal and proximal) identities. This is related to *entitlement to experience* or more precisely in this analysis the entitlement to knowledge. As Sacks told us:

> The occasions of entitlement to have experience [or knowledge] are carefully regulated. And, insofar as part of the experience involves telling about it, that that's one of the ways in which you lay yourself open to having e.g. made too much of it, experienced it [understood it] wrongly etc.
>
> Sacks, 1992: Volume II, Part IV, Spring 1970, LC 4: p248.

Importantly, when doctors request a patient to report on what Dr X *said* or *did*, or what they *found* it could be seen that this is precisely what patients will do. Again,

[31] Unlike Svennivig's (1999: p306) observations of casual conversation, "common background information is not always presupposed", but is "established explicitly" because "local concerns require it".

this suggests an orientation to the difficulty of doing 'other authored' speech[32]. As Dingwall (1997) notes, interviews are 'a situation [in] which respondents are required to demonstrate their competence in the role in which the interview casts them' (p58). The cancer consultations require similar demonstrations of competence, from both doctors and patients and here we have seen how these requirements are fulfilled and produced through differing configurations of questions and answers. The patients also invoke their relationship to the information reported and their 'rights' in relation to the reported information.

Later, in *Chapter Four*, we discussed how the two 'perspective' display devices (1) foreshortened with a continuation of history taking or (2) full series with agreement / correction and confirmation / evaluation, are ways of ensuring that all are 'on message' or 'mind on' (Wooffit, 1992). An *I'll-assume-nothing-philosophy* (both topically and relationally) is evidenced in and through the cautious elicitation of what patients know already about their cancer or are likely to know as implied in and through their report of what other doctors have told them.

The foreshortened perspective display involves a Q-A-Q turn organisation. It serves a function of establishing patient knowledge before doing cancer talk, and is used flexibly, alone or in combination with other knowledge soliciting or alignment devices. The placement during the data-gathering phase of the consultation is crucial to our understanding about the 'missing assessment', evaluation, confirmation or disconfirmation and the use of un-prefaced questions in third position. Activity types are tied to 'phasing'; the place in which the work is being performed is crucial (ten Have, 2001). Indeed, 'missing assessments' (Jones, 2001) in third position are not unusual in these kinds of meetings where history taking (hence Q-A chain) or data gathering is an important part of the business at hand[33].

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[32] In some ways when patients are invited to 'do' reported speech, this might remove some of the pressure from them – they are not so heavily implicated in the content of the 'other' authored speech when compared to their own feelings. Patients become the 'link worker' between health professionals.

[33] Jones suggests the consequences of no assessment or response to patients informings (2001):

> Patients subsequently exhibit, through pausing and withholding speaking, that they expect a different type of response from physicians. Hence, gaps occur when assessments might be due... marking them as missing. After these gaps... physicians disattend the lack of assessments, instead continuing with the 'business as usual'
>
> Jones, 2001: p113.

As already suggested, the ideal of an immediate response to patient-provided information arises out of a comparison with ordinary conversation (ten Have, 2001). To compare this with talk in work place settings makes little sense (see p256). Doctors may hearably not be ready to proceed to information delivery. Rather, they may continue to solicit precisely what patients have gleaned from other meetings at other temporal moments on their illness paths. Patients attend to the Q-A-Q organisation and collaboratively uphold and endorse the ritualised 'normal form'.

Unlike the foreshortened and full perspective display invitations, the Summative Knowledge Proposal ('as I think you know' / 'as you know') only invites minimal input from patients. The doctor at H2 deployed the proposal early in the trajectory and the clueing, guessing and establishment of the patient journey to the diagnosis counted as an adequate basis for the doctor to interactionally conclude *this is a patient who knows the situation and I can now tell them about treatment.* The absence of the PDS did not seem to result in any obvious misunderstandings at H2. However, there did seem to be more turbulence in the talk from the doctor when proposing the knowledge of cancer[34].

The downside of the knowledge proposal is that adjacency is not so clearly present and so only minimally solicits confirmation of the proposed knowledge. The proposal does not get close to soliciting a patient's prior knowledge or understanding[35]. One might argue that the upside of the knowledge proposal is its speed, but limited 'information' is gleaned in this way. Seeking more active patient alignment is a neat way of making it known to patients that their perspectives are important and those perspectives prove useful. The perspective display series:

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[34] There are consequences in terms of how much information is provided. During patient responses to the open interrogatives patients get to 'speak up' and even if they stick fairly tightly to the project of the questions, issues of "preoccupation" are often "leaked" and this can be useful to doctors. Indeed, where misunderstanding is shown, we have seen how a doctor might tailor information delivery so as to manage such misunderstanding.

[35] As previously suggested, the proposal of knowledge that the cancer diagnosis is 'owned' relies on conversation "operating with a local cleansing of itself". As Sacks (1992) told us:

> ... The non-occurrence of one of those remedial questions (what, why, etc.) serves as evidence for the non-need to cleanse our current state. ... Unless you indicate that what I said was, e.g. unclear, or that you didn't hear it - which is to be done with some set of terms and rights after I said it – then it's to be treated as though what I said was heard, and was clear.
>
> Volume II, Part VIII, Spring 1972, LC5: p560.

> ...can be seen as a form of acknowledgement that lay perspectives are routinely taken into account by health professionals when dispensing expert advice.
>
> Sarangi, 2001: p3-11.

Indeed Maynard states thus:

> A further effect of using the perspective-display series is to portray the clinician not as one whose assessment is an independent discovery, nor the parent as one who must be moved from a state of ignorance to knowledge.
>
> 1992: p352.

Patient contributions in response to all of the questions tend to vary; sometimes the depth of information is notable, but at other times simple answers such as "the surgeon said the operation was a success" are provided. In discussing a data example drawn from medical interviews and low participation from patients, Stivers and Heritage (2001) note:

> The minimality of the patient's responses exhibit his understanding of the 'checklist' status of the questions and his preparedness to comply with that understanding.

Later they add:

> Nonetheless, ... patients' responses are not exclusively restricted to providing answers to doctor's questions... The additional material – whether addressing a difficulty in responding, adding supporting details, pre-empting negative inferences, or a narrative departure – can be used to accomplish a range of ancillary tasks. Most significantly, they indicate features of the patient's lifeworld....
>
> p178-9.

In Chapters *Three* and *Four* we saw some examples of how patient-delivered information may "leak" these "life world" concerns, whether produced in relation to an 'open' or 'closed' interrogative or a full or foreshortened perspective invitation (OQ). Whilst closed interrogatives did not rule out expansion / correction, the Summative Knowledge Proposal did so. Active patient participation has been encouraged in much of the literature on communication in the medical setting and here

we have clear evidence of *how* the use of 'open' questions (and of course the work that occurs thereafter) is one way of ensuring this participation. Importantly, in these chapters we also have evidence for how patients may respond to such questions and the benefits that these might have in terms of patient and doctor establishing a 'common ground'.

It should be plain that to simply assert that history taking involves the doctor asking questions and patients providing answers can belie the subtle and differing questions used to make history taking possible. In addition, the analysis of history taking underscores clearly the importance of contextualising analytic descriptions within the broader context of meetings, with due consideration for next actions and activities along the trajectory of the consultation. For example, to simply describe the 'closed' interrogatives during early history taking would have fallen short by obfuscating the combination of approaches that may be used by any one doctor in any single consultation.

Next, in *Chapter Five*, we move to look at how doctors move on from the end of history taking to (continue to) embellish patient diagnoses and I examine how this paves the way toward treatment talk.

PART THREE –

DIAGNOSTIC AND TREATMENT TALK

PART THREE is again separated into two chapters. The first, *Chapter Five*, details how, following history taking, doctors and patients produce evidence about patient diagnosis and how they move in a stepwise fashion to discuss treatment in the light of the diagnostic details shared. As well as detailing the 'stepwise build', analysis details the 'voices' used by doctors whilst doing evidential citation.

The second, *Chapter Six*, discusses in more detail how information about diagnosis and treatment is organised. Relatively good, bad and uncertain news is shared and the organisations that contribute to this accomplishment are described: the 'pairing phenomenon' and the 'power of proximateness'. The simultaneous accomplishment of an omni-relevant optimistic frame whilst discussing diagnosis and treatment is also examined. The benefits and losses of organising news in the ways described are discussed.

5.

Giving evidence and accomplishing the diagnostic context for treatment

> [Diagnosis] involves a balancing act between two potentially conflicting orientations: an "authoritative" orientation toward the realm of medical reasoning belonging exclusively to the doctors and competing orientation toward the expectation that the doctors, in their interactions with patients, will treat the diagnostic process as observable and intelligible and that they will justify their diagnostic statements methodically through reference to the evidence for the diagnosis.
>
> Peräkylä, 1998: p317.

> In theory, physicians do not have to deliver diagnoses. For example, after privately arriving at a diagnosis, physicians could simply treat patients' problems. However, such omission is non-existent in my data of modern (1995-1998) American visits.
>
> Robinson, 2003: p42.

5.1 Introduction

In this chapter, the delivery and receipt of diagnostic and treatment information are considered. First, I provide an overview of how doctors build towards announcing their treatment disposal. When viewed sequentially, the build can be properly appreciated as gradual. Doctors first provide patients with evidence of the diagnosis and then use the evidence provided to describe the implications in terms of treatment. Often they then cite further evidence of diagnosis, so that the treatment becomes wrapped in diagnostic evidence.

Second, I consider one feature of the action of providing evidence about diagnosis and treatment. In particular, Goffman's (1981) concept of 'footing' allows a clear look at how doctors invoke their agency in relation to the information delivered. I suggest that the impact or function of employing different 'voices' is related to the credibility bestowed upon the information shared and, in turn, the doctors who deliver the information. I suggest that in employing different 'voices', in similar vein to *Chapters*

Three and *Four,* doctors continue to orient to the important role of other health care professionals not present in the consultation. In so doing they avoid appearing to solely rely on their own individual authority. So too, the citation of evidence in and of itself avoids a sole reliance on their authority and accords patients with a 'theoretic capacity' to understand and make use of the information shared.

5.2 Organization of this chapter

In *Chapter Three,* we saw how doctors and patients establish a common ground during history taking in terms of the patient journey to diagnosis. In *Chapter Four* we also established that further doctor-delivered information about diagnosis and treatment is generally only provided once patients display some understanding or knowledge of their diagnosis; often solicited by enquiring about what other doctors have told them at previous points along the illness trajectory. All of this 'history taking' work paves the way for further talk about cancer. This chapter examines how doctors (and patients) embellish patient diagnoses and discuss treatments. Extracts are (mostly) taken from consultations following the completion of the task of history taking. Thus, I continue to trace the unfolding order of the consultation trajectory.

The chapter is organised into two sections. The first (*Section 5.3*) provides a sketch of how doctors move from diagnostic embellishment through to talk about their treatment recommendations. The section provides a window on how institutional agendas are pursued in the potentially *sensitive* space of the cancer consultation. Based on his examination of primary medical care encounters, Heath (1992) notes how the act of diagnosis is related to and forms the "basis" for the "management of the complaint". In similar fashion, the embellishment of diagnoses in the meetings analysed in this thesis leads to the management of the cancer diagnosis and this involves detailing chemotherapy or radiotherapy.

Although the information provided in the meetings analysed in this chapter is more detailed than that routinely found in primary care meetings, and the topics under discussion may be classified as more serious and complex, the organisation of talk is similar to that reported in the primary care medical meeting. These similarities

suggest that on a general level, a medical meeting 'project' or "large scale structure" (Robinson, 2003) appears to traverse a number of consultation types, in both primary and secondary care, to ongoingly shape "communicative behaviour".

In *Section 5.4,* I focus on one recurrent phenomenon to show *how* diagnostic informings and the consequent discussion of treatment can be accomplished. Fragments are again extracted after history taking to show how, in reciting the evidence, doctors shift their footing; they speak on behalf of themselves, on behalf of others and they report others' words and actions. The function of different 'voices', especially the use of 'we', is considered. For example, by speaking in the voice of 'we' oncologists continue to draw on resources that are external to the consultation, such as other doctors, test results, activities undertaken by the team, general processes of medical assessment of risk and patient notes. This appears to achieve an air of objectivity and credibility (see Clayman, 1992; Maynard, 2003; Heritage, 1985). That is, it is not just the doctor in the *here-and-now* delineating lymph node involvement or recommending chemotherapy, but the pathologist, surgeon, other health care professionals and written-technical evidence.

Once the method of evidential citation has been documented, I turn to Peräkylä's (1998) work on the communicative practices found in over 100 primary care meetings in Finland. His examination of diagnostic explication provides a useful way of theorizing the import of the very presence of evidential citation in the oncology consultation. In similar vein to Peräkylä, it will be suggested that the provision of diagnostic evidence to forecast and support a treatment disposal suggests an orientation by doctors to their accountability and, thus, a resistance to a sole reliance on their medical authority (Peräkylä, 1998).

A focus on how doctors deliver diagnostic information and build towards treatment talk and treatment recommendation requires at least some discussion of what patients do in these meetings. Whilst the patient role is somewhat sidelined in this chapter, *Chapter Six* moves away from the focus on doctors to describe some of the features of patient reception.

To summarise, this chapter will examine:

1. How doctors organise / structure the provision of diagnostic and treatment evidence in a stepwise fashion.
2. The use of the voice of 'we' during the citation of diagnostic evidence and the move to mention further treatment.
3. The significance of detailed evidential citation.

One reason I became interested in the broad tasks of 1 and 2 above is the fascinating practical problem potentially faced by doctors in the consultations considered here. And that is how to demonstrate the success of the prior treatment, whilst still encouraging further treatment. Unlike some who seek health care advice at the primary care level, patients dealt with in the cancer setting generally do not (in an ideal world) want (to need) further treatment, so how to get patients to realize the benefits when a surgical procedure has already been undertaken is important[1]. Speaking in general terms, one way of engaging patients seems to be the actual act of calling forth the evidence of diagnosis to support the recommendation for chemotherapy or radiotherapy.

5.3 Calling forth the evidence: The logical build towards treatment talk

In this section, I sketch the way in which the tasks of diagnostic embellishment and then treatment talk are organised in relation to one another. In so doing, I hope to provide useful information on how doctors produce logical links between separate though related pieces of information. Following Heath (1992) and his investigations of communication in primary care, the 'diagnosis of a complaint often leads to the management of the complaint'.

One exemplary case is drawn on in detail to demonstrate how evidential citation builds towards treatment talk and treatment disposals. Two further cases are shown to briefly illustrate this stepwise progression. Focusing on a single case, rather than

[1] Thanks to Jon Hindmarsh for discussion around this potential practical problem.

developing analysis in detail across all or a selection of cases, allows a demonstration of the sequential build. Thus, whilst the breadth of evidence is diminished, the depth, in terms of the topical and sequential build, is not.

Using consecutive sequences makes it easier to see how analytic claims of smaller segments hold up when placed in the broader context of surrounding talk. It also demonstrates the ongoing orientation to next activities. In line with Robinson's (2003) analysis of doctor-patient interaction in the primary care medical meeting, participants orient to current actions as building towards a next activity and ultimately the final activity of the consultation or 'project', that of the delivery of a treatment disposal and progression to the management of the complaint (Heath, 1992).

Let us view a series of consecutively drawn extracts (*Case 1*) to see the logical build from 'as you know' or 'as you rightly say' it was cancer, through to the embellishment of diagnosis, risk and latterly the treatment implications in light of that risk. In *Extract 5.1a*, following a perspective display from the patient, a 58 year old woman with breast cancer (first shown in *Chapter Three*), the doctor uses the patient's display to co-implicate her in some knowledge of cancer (1-2) and moves to embellish the diagnosis in the context of their *shared* knowledge.

Extract 5.1a (Case 1.)

01	Dr:	.hhh ((clicking of teeth)) <as ↑you> QUIte r↓ightly say
02		you've had (.) the mastectomy (.) and that's removed the
03		can↑cer =
04	Pt:	=mmm=
05	Dr:	=and we would hope that that has been cura↓tive (.) but we
06		kn:ow there is a ↑risk of recurrence of the cancer (.) AND (.)
07		the ↑risk of ↓recurrence could be either >locally< (.) or
08		elsewhere in the body=
09	Pt:	=yes=

Before beginning to provide information that the patient is possibly not familiar with, the doctor co-implicates her in the knowledge about what has been done so far by drawing on the patient's prior perspective display (not shown) "<as ↑you> QUIte r↓ightly say you've had (.) the mastectomy (.) and that's removed the can↑cer =" (1-3). Following, the

patient's minimal response token "mmm", using the turn extension device "and", the doctor elaborates on this initial announcement to tentatively suggest a positive gain from the treatment route already taken, "and we would hope that that has been cura↓tive (.)..." (5). Next, by using the contrast marker "but", the doctor shifts the direction of talk and raises the spectre of future risk in general, "but we kn:ow there is a ↑risk of recurrence of the cancer (.) AND (.) the ↑risk of ↓recurrence could be either >locally< (.) or elsewhere in the body=" (5-8). Once a *generalised* risk of recurrence has been raised, the doctor moves to tie that risk to the patient's case in *particular*.

Extract 5.1b (Case 1.)

01	Dr:	=the risk of lo:cal recurrence would be very ↓low because
02		you've had a mastectomy
03	Pt:	mm
04		(.)
05	Dr:	but there is a risk of (.) recurrence elsew↑here and that's
06		de↑spite the fact you (.) had <a chest x-ray which is normal>
07		and all your blood tests are normal (.) °okay° (.)
08		.hhh <NOW> the ↑reason (.) that we can tell there's a risk is
09		by look↑ing (.) at what the cancer looked like under the
10		microscope.
11	Pt:	yes
12	Dr:	°okay° (.) and if I go through that (.) with you (.) and explain
13		what that means=
14	Pt:	=yes=
15	Dr:	=and: (.) explain <therefore> why we'd ↑like (.) <why we
16		think you should have chemotherapy treatment> I'll then
17		explain what the chemotherapy in↓volves (.) al↑right
18	Pt:	Okay

Once the risk of recurrence has been announced, the doctor continues to cite the evidence as it relates to the patient, "=the risk of lo:cal recurrence would be very ↓low because you've had a mastectomy (1-2)". Following another minimal response token from the patient "mm", the doctor again uses the contrast marker "but" to shift the direction of talk to re-emphasize that there is still a risk (5)[2]. The doctor ties the evidence cited to

[2] The doctor's turns have a number of features that create and maintain an *expert* view. When he elaborates further on the evidential basis for his claims he states, "normal x-ray", "normal blood tests"

the issue of treatment, and via another agenda statement he forecasts further information delivery about what the information means and why it leads to a disposal for chemotherapy. Following a recitation of the diagnosis, the doctor produces the upshot of that news by delivering the treatment disposal (15-17).

In *Extract 5.1c*, we see evidential citation occurring and then the mention of chemotherapy foreshadows further discussion of the factors (about chemotherapy) that inform the decision. Thus, evidence is placed before and after the introduction of chemotherapy; chemotherapy becomes wrapped in supporting evidence.

Extract 5.1c (Case 1.)

01	Dr:	=al↑right (0.5) the FACTors that make me say that (.) are the
02		s↑ize, the growth into blood ves↑sels, the FACT[3] that (.) the
03		lymph nodes were involved (.) <and also> that it was oestro-
04		receptor negative (.) so (.) I think you should have (.)
05		chemotherapy ↑treatment. the ↑reason I say that <is that>
06		chemotherapy treatment has been shown to reduce the risk of
07		re↑currence (.) and also to improve survival=
08	Pt:	=°yes°=

The doctor states that chemotherapy can reduce the risk of recurrence. He *does* fairness (not shown) as in, "=although to be FAIr in both groups there would be people who were perfectly ↑well (.) and people for whom the disease would have come back (.)" and avoids the disposal being conveyed as non-negotiable.

I want only to make one broad point here. It is clear from *Case 1* that a stepwise organisation of information delivery is accomplished. Doctors recurrently begin with an announcement about the shared knowledge that cancer is the diagnosis, next they introduce the notion of a generalised risk among *all* cancer patients, they then tie that risk to the patients' *particular* medical profiles, which usually involves explicating their lymph node status. In light of the evidence of an elevated risk, doctors produce

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and "looking at the cancer under the microscope". His medical frame displays his expertise and produces evidence that builds towards a treatment disposal (Peräkylä, 1998).

[3] Although I have not looked at the prosodic features in detail, it is interesting that 'fact' gets emphasized in this way. 'Facts' are rarely contestable, not subjective, but true. Adding emphasis in such a way underscores the facticity of lymph node involvement.

the consequent ameliorative course of action in the form of a treatment disposal. Evidence is then produced for the disposal. The same organisation of giving evidence can be seen in *Cases 2* and *3* below. Again, the extracts are lengthy to allow a broader view of how doctors organise their information delivery in a stepwise fashion.

Extract 5.2a (Case 2).

01	Dr:	°okhay° (.) .hh (.) as I ↑think you (.) ↓kno::↑w from the
02		conversation you had a cancer (.) of the bow::el:↓
03	Pt:	°yes°
04	Dr:	which has been removed.
05	Pt:	°yes°
06	Dr:	and ↑loo:king at it (.) at the opera↓tion (.) Mr X the surgeon
07		felt he had °re↑moved (.) ↓everything°. (.) .hhh and thatt (.)
08		<↑really> has been confirmed on looking at (° under the
09		microscope°) (.) ↑yes:s the ↑tumour <the cancer> had gone (.)
10		through the bowel wall. but where he cut (.) around was clear
11		of that
12	Pt:	yes right
13	Dr:	AND he removed ↑ten ↓lymph nodes. which were at↑tached
14		(.) to the bowel.
15	Pt:	right
16	Dr:	.hhh and none of those ten lymph nodes had (.) cancer (.) in
17		them
18	Pt:	oh right=
19	Dr:	=al↑right=
20	Pt:	=right
21		(1.0)
22	Dr:	<HOW↑ever> one of those cancer cells- er one of (.) those
23		lymph nodes. had some cancer >clo::se< to i↑t:
24	Pt:	right
25		(0.5)

In *Extract 5.2a,* the doctor proposes the shared knowledge that cancer is the diagnosis, and proceeds to embellish the patient's cancer diagnosis by alerting the patient about his lymph node status. Although lymph node negative, the proximity of the lymph nodes to the bowel wall complicates the patient's case in *particular*. In *Extract 5.2b* below, in similar fashion to *Case 1*, the doctor then proceeds to explain the relevance of lymph nodes in *general* terms and then moves to talk about lymph nodes in relation to the patient's case in *particular*. He also raises the risk of spread when lymph nodes are involved.

Extract 5.2b (Case 2).

01	Dr:	hh the ↑reason we take lymph nodes ↓out (.) is that the
02		↑lymph nodes are <sort-of> the first port of call: <if you
03		like>=
04	Pt:	=ye:es
05	Dr:	↑if any cancer cells are going to go elsew[here.
06	Pt:	[°that's right (to other or↑gans and)°=
07	Dr:	=AND we've looked <u>into</u> the ↓lymph nodes to see if any
08		cancer cells have settled (.) ↓<u>in</u> those lymph nodes. (0.3)
09		and in ONE of the lymph nodes (.) there was some cancer
10		cells go↑ing (.) ↓close to that lymph ↓node
11	Pt:	right
12	Dr:	↑NOW (.) >be↑c<ause of ↓that we can't say (.) that there
13		definitely were cancer cells ↓ther[e]
14	Pt:	[no]
15	Dr:	but obviously (.) seen as those the cancer cells were close (.)
16		↑to ↓i:t=
17	Pt:	=then you'[ve (got to be cautious)
18	Dr:	[RAISEs that sort of sus[picion.
19	Pt:	[<↑yeph ↓yeph>
20		(1.0)

Once the diagnosis is embellished and the patient and doctor have established the patient's lymph node status and the relevance therein expressed as a "suspicion", below in *Extract 5.2c*, the doctor moves in a similar stepwise fashion to highlight the treatment implications in the light of the patient's diagnosis, including his lymph node

status. At lines 2-4 the doctor introduces the relevance of lymph nodes in relation to chemotherapy decision-making and this foreshadows further talk about lymph nodes.

Extract 5.2c (Case 2).

01	Dr:	.hh if I could ex↓pla::in <a little about the> im>por↓t<ance
02		of (.) the lymph nodes. (.) ↑IF there were any lymph nodes
03		with cancer cells (.) in them. >then< there would be no
04		question °<that you should have chemotherapy treatment>°
05	Pt:	°right°
06	Dr:	°al↑right°
07		(0.2)
08	Dr:	.hh in ↑THOSE patients where the lymph nodes are ↓not
09		invol:ved ↑then (0.2) we'd ↑look at that: <sort of> on it's
10		individual merits.
11	Pt:	yes
12	Dr:	<sort of> how ↑big the tumour ↓was (.) and if there is
13		anything ↑else there which would (0.1) make you think there
14		is an increased risk.=
15	Pt:	=yes yeah
16	Dr:	and I ↑think these (.) lymph- <was it these> tu::mour cells
17		that we saw (.) going close ↑to that (.) lymph ↓node
18	Pt:	mmm
19	Dr:	do:: <sort of> raise (.) alarm [bells <if you like
20	Pt:	[<bit of a light bulb ↑yeph>
21	Dr:	<but>- they could have=
22	Pt:	=yes=
23	Dr:	=gone there=
24	Pt:	=yes
25	Dr:	al↓right (.) and ↑THEREfore al↑>though< (.) this was
26		lymph node ↓negative (those ten lymph nodes) I ↑think (.)
27		that you should have chemo↓therapy =
28	Pt:	=<yeah>=
29	Dr:	=treatment=
30	Pt	=<yea yeah>=
31	Dr:	=°al↑right°
32		(2.0)

Finally, following quite detailed explication of the lymph node status of the patient, at lines 26-27, the doctor announces the treatment implications and in particular his proposal that chemotherapy treatment *should* be pursued.

Doctors tend to contextualise the treatment talk in the diagnostic evidence (both before its mention and afterwards) and it is this evidence that provides the logical basis for the doctor's recommendation to treat. The evidence is wrapped around the chemotherapy disposal and works to support the disposal in quite strong terms. In some ways, providing evidence greases the wheels for patient agreement. For a patient to say "I do not want chemotherapy" when the evidence in favour of the treatment has been provided in clear terms is more difficult than if it were proposed without the grounds for such a proposal being made accessible to the patient.

I now move away from describing the stepwise movement to consider briefly the practical problem of ensuring patients *see* the (potential) reasonableness of further treatment, whilst also invoking the success of prior treatment. If we just skip back to *Extract 5.2a*, we can see that at line 4 the doctor announces that the cancer has been "removed", at 7 this is further reinforced by the doctor's report that the "surgeon felt he had removed everything" and this is again backed up by the viewing of microscope images. Here, we can see that the doctor invokes the success of prior treatment, before explicating the lymph node status of the patient. It is the lymph node 'news' that provides a rationale for further treatment and this is explained in *Extract 5.2b*.

It is a recurrent feature in these meetings that doctors stress the *removal* of cancer, that is the *success* of prior treatment, and then embellish the diagnosis to secure a position from which further treatment can be hearable as a reasonable course of action, despite the success of surgery. The stepwise progression of the evidential citation steadily manages the practical problem of ensuring patients can see reason in the forthcoming recommendation for further treatment, without causing alarm by intimating the futility of the surgery already performed. In short, further treatment is contextualised in such a way as to imply the added value from further (potentially successful) treatment.

In *Case 3*, the doctor has seen the patient before, just the day before in fact, and at that point the doctor had discussed the diagnosis. This prior meeting accounts for the doctor's early treatment announcement. Notwithstanding, the early announcement of the treatment disposal is rapidly followed by a detailed explication of the evidential basis for that recommendation. This shows that doctors wrap their recommendations for treatment in evidence, with the evidence being produced before or after the recommendation (or both).

Extract 5.3a (Case 3).

01	Dr:	it's only been twenty four ↓hours- <↑less than> twenty
02		four hours since we last met [wasn't it]
03	Pt:	[yes]
04	Dr:	Mr X wanted to check you and a:=
05	Pt:	=yes
06		(.)
07	Dr:	u↑m: (.) the ↑upshot of it all is, until yesterday we didn't
08		have the final re↓port from the patholo↑gists (.)
09	Pt:	yes
10	Dr:	umm:: it's a↑vailable ↓now, it's certainly shows that it's:
11		(.) advisable for you to ↑have this radiotherapy=
12	Pt:	=yes=

Here in *Extract 5.3a*, when compared with *Extracts 5.1* and *5.2*, we see a more forthright expression of the doctor's treatment line. It is made at an earlier juncture in the interaction, without a detailed evidential citation of the nature of the diagnosis. As already mentioned, this is easily accounted for by the fact that the doctor and patient had arranged to meet to discuss treatment in light of the test result that they were waiting for. Despite the citation of diagnostic evidence the day before, however, the doctor proceeds to produce the evidence in detail, which again works to support the proposal of radiotherapy being "advisable".

Extract 5.3b (Case 3).

01	Dr:	=um:, I mean (2.0) there <u>was</u> of course tumour- cancer in (.)
02		that tonsil area (.) and there was that lymph gland in the
03		↑neck
04		(1.0)

05 Dr: pathology looks although it's completely different from that
06 tumour you had in the b↑ladder a couple of years ago=
07 Pt: =oh right
08 Dr: it's not the same (as the last one). DOUBLE BAD LUCK,
09 I'm afraid anyway BOTH OF THEM HAVE BEEN
10 OP↑ERABLE
11 Pt: yes I- [yes=
12 Dr: [er it's been removed, um: the problem we have is that
13 when we remove ↑cancers (.) um: we're never 100 percent
14 sure that it's all gone even though it l↑ooks as though it has
15 Pt: yes
16 Dr: and sometimes it can leave little <sort of> ↑roots in the (0.5)
17 tissue surrounding the area. the pathologist ↑THINKS it's all
18 taken away but you can never be ↓sure=
19 Pt: =no=
20 Dr: =it-it certainly had spread to some of the glands in the
21 n↓eck=
22 Pt: =yes=
23 Dr: =and when it's done that (.) sometimes there can be little
24 seeds between the glands that (.) the surgeon nor the
25 pathologist can de↑tect (.) so there could be some of those
26 there, we're not ↑su↓re.
27 Pt: no

As in the previous examples, the doctor produces the lymph node status and discusses the relevance of that in terms of spread, "roots in the tissue surrounding the area" (16-17). He then returns to the topic of treatment by producing the treatment upshot once more.

Extract 5.3c (Case 3.)

01 Dr: but radiation's a very effective way of ↑dealing ↓with ↓them
02 Pt: I understand=
03 Dr: =y:es so that what we- that's what we've got plan↑ned
04 Pt: yes[4]

[4] In fact, this patient already seems to know that radiotherapy is recommended. He does not mark the "planned" radiotherapy as news for him, but simply concurs through the "yes" receipt that radiotherapy is indeed planned. Here we see how even when doctor and patient have met before and gone over the 'plan' on a prior occasion, when new information is forthcoming which supports the plan, the links between diagnosis, tests and further treatment may be re-asserted.

The doctor again makes the disposal known following the evidential citation. Again, returning to *Extract 5.3b* briefly, we see how doctors secure a context which suggests the success of prior treatment, "been removed" before moving to explicitly orient to the requirement for further treatment. Commonsensically, ensuring patients realise the benefits of adjuvant chemotherapy or radiotherapy is easier in a context where the patient is clearly told that the treatment already carried out has helped (i.e. removed the cancer). This invokes a broader message that *treatments-can-and-do-work.*

5.3.1 A summary

More generally, when sequences of talk are examined in this way, the institutional mantle of these meetings is clear. It is plain that doctors orient to the task of providing diagnostic evidence to patients and this forms the basis for the medical judgement that radiotherapy or chemotherapy is required. Robinson's (2003) examination of interaction in primary care settings describes a similar ongoing orientation to a "project" or "large-scale structure"[5].

> The establishment of a new medical problem makes relevant a large-scale structure or project, of interaction that shapes the production and understanding of communicative behaviour. The project has, as its ultimate objective, the solution of patients' problems, which is treatment. However, treatment is contingent upon diagnosis, which itself is contingent upon physicians obtaining information about patients' problems, which is initially garnered from patients' presentations of their problems and subsequently from history taking and / or physical examination. Importantly, physicians are accountable for progressing in a directional fashion through the project's roughly ordered sequence of medical activities to its completion.
>
> Robinson, 2003: p 47.

In line with Robinson's (2003) suggestions, in the oncology meetings discussed here, each 'piece' of information is contextualised in the immediately preceding talk. For example, we recurrently see prior successful treatment being oriented to, diagnoses

[5] Robinson (2003) shows how certain lexical choices, such as 'so', enable doctors to move from diagnosis to treatment. However, to look at the details of the transitional moments or topic shades from diagnosis to treatment would add little to the literature.

embellished or re-confirmed and the consequences explicated in terms of and encircled by the benefits of further treatment[6].

Stepwise evidential citation

There were lymph glands removed	
↓	
Most of those lymph glands were okay	
↓	
There were some with little spots of cancer	
↓	
That is a sign that cancer can spread	News upshot
↓	
It doesn't mean that it has spread elsewhere	Mitigated news upshot
↓	
But as a precaution we will give you some radiotherapy	Treatment disposal
↓	
(Sometimes) further evidence to explicate the benefits and rationality of treatment	

The logical elaboration of information, though not strictly syllogistic[7] in character, does have a certain stepwise feel to it[8]. The doctors first produce the generalised risk that faces all people who have had cancer and (for most) an operation to remove that cancer. In so doing they set up the implicit message that cancer patients, in the here and now, are also at risk. These announcements pave the way for information that is particular to patient cases. Throughout, doctors topic shade and spell out the links between the various pieces of information. Patients respond to the information as in a

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[6] Robinson's (2003) comment also nicely summarises the import of the preceding chapters about history taking. He reminds us how the diagnostic explication above is (in part) made possible through patient displays of how they came to be diagnosed and what they know of their cancer so far.

[7] Gill and Maynard (1995) state thus: "In formal logic, a syllogism contains a general (major) premise followed by a particular (minor) premise and a conclusion, as in this example: 1) general premise: all children are funny; 2) particular premise: Jimmy is a child; 3) Conclusion: Jimmy is funny. When using "incomplete syllogism" for delivering diagnostic news, clinicians do not overtly state the conclusion, and instead leave the recipient to draw the conclusion (p17).

[8] As Robinson (2003) notes, "physicians display that the treatment recommendations relevantly and accountably follow diagnoses" (p43). However, the 'complex' nature of cancer and 'uncertainty' surrounding cancer and its treatment adds an additional layer of interactional work. This involves doctors directly orienting to the uncertainty of cancer and hence mitigating any claims that can be made or stated about the potential for a successful treatment outcome (See *Chapter Six*).

statement-response adjacency pair, so doctors' turns are punctuated by patient continuers and news receipts. This turn-taking gives the impression of the information being produced in small chunks, and not long uninterrupted doctor delivered narrative segments. Nevertheless, the information is complex, and often involves an in situ commitment from patients to align to doctors' disposals to provide a treatment that might kill good cells with bad (McKenzie, 1998).

That doctors appear to organise their information delivery in such a 'stepwise' fashion might not be altogether surprising. This is a feature of casual and institutional conversation, noted long ago by Sacks and I quote at length:

> It's a general feature for topical organization in conversation that the best way to move from topic to topic is not by a topic close followed by a topic beginning, but by what we call a stepwise move. Such a move involves connecting what we've just been talking about to what we're now talking about, though they are different... Now, this stepwise thing is a really serious feature of topical organization, and it's my rough suspicion that the difference between what's thought to be a good conversation and what's thought to be a lousy conversation can be characterized that way, i.e., a lousy conversation is marked by the occurrence of a large number of specific new topic starts as compared to such a conversation in which, so far as anybody knows we've never had to start a new topic, through we're far from wherever we began.
>
> Sacks, 1992: Volume II, Part VIII, Spring 1972, LC5: p568.

By detailing the stepwise progression and the apparent 'smooth' topic transition, we detail for others how this work can be (and often is) accomplished. In short, it renders visible the "seen but unnoticed" practices involved in the production of the everydayness quality of these potentially tricky information-sharing moments. Here we are reminded that there is indeed a lot to learn from what members do everyday and how "good" information sharing (as opposed to "lousy") may draw on everyday skills that 'we' all possess (to some degree).

In the next section (*5.4*), I focus on doctors' footing whilst they produce evidence about diagnosis and treatment.

5.4 Calling forth the evidence: Invoking the "voice of Medicine"

> Across a variety of settings, interactants have the option of speaking on their own behalf, or on behalf of another or a collection of others, or on behalf of themselves and others jointly...
>
> Clayman, 1992: p196.

> In interaction with the patient, the doctor systematically accomplishes the factual status of his professional opinion; an objectivity which is rarely challenged.
>
> Heath, 1992: p238.

There is a lot at stake in the meetings analysed in this thesis and in medical meetings more generally. Doctors (and patients) have to relay complex information and use that information to underscore the importance of further treatment. In this next section, we see how doctors draw on different 'voices' whilst producing the evidential basis for diagnosis and treatment and further invoke the relevance of other actors.

Goffman's (1981) concept of 'footing' is useful for framing the positions that speakers and hearers adopt in relation to words that are spoken and heard. Goffman produced an initial statement on 'footing' in 1974 (pp496-559). Later he summarised the concept of footing during a discussion of 'changes in footing' by re-examining 'speaker and hearer' actions. He states thus:

> A change in footing implies a change in the alignment we take up to ourselves and the others present as expressed in the way we manage the production or reception of an utterance. A change in our footing is another way of talking about a change in our frame for events. ... [P]articipants over the course of their speaking constantly change their footing, these changes being a persistent feature of natural talk.
>
> 1981: p128.

Parties to talk may produce information / views in the "footing" of "animator" (vocalises the words), "author" (the sentiments or meaning expressed in the spoken words are those of the speaker), or / and "principal" (the speaker establishes their

position in relation to the information shared through the words spoken) (see Goffman, 1981: p144-145). Speakers can shift between these various footings on a moment-by-moment basis or may choose one as a "home base" "participation format" for the entirety of their turns at talk. Goffman states further:

> The notions of animator, author, and principal, taken together, can be said to tell us about the "production format" of an utterance.
>
> 1981: p145.

Goffman's (1981) 'footing' aids an understanding of how doctors produce evidence and how the "production format" enacted is significant for how their (and patient's) agency is set up in relation to the information shared.

Drawing on Goffman, Clayman's (1992) examination of news interviewers' footing whilst producing hearably controversial viewpoints showed that by adopting the role of "animator" of the statement as opposed to the "author" of the viewpoint expressed, they served to invoke a "neutral" position. Consequentially, news interviewers managed to avert or diminish responsibility for the words spoken and hence produce their actions in a solidary fashion, again lowering the potential for interactional problems.

Maynard's (2003) examination of communicative practices in a range of clinical settings shows that doctors will often adopt a footing of "animator" of the news produced and that this has the effect of distancing them from the news delivered. More particularly, when the news being delivered is potentially delicate in nature or of a 'bad' news variety, doctors will avoid a situation of "blaming the messenger" by adopting a neutralistic footing.

> It can be said that professionals who deliver bad news appear to eviscerate displays of their agency and responsibility, thus avoid blame for the news.
>
> Maynard, 2003: p219.

Here I suggest that Clayman (1992) is writing about a situation where "distancing" is relevant. That is, news interviewers do not want to appear to be making controversial

claims. By contrast, in a medical context, such as that dealt with in this study, it appears that doctors are not necessarily concerned to be "neutral" or to avoid responsibility for what they are saying, but are concerned to demonstrate that their claims and words are soundly based and collegial. So, contra Maynard and Clayman, it seems that although footing plays an important role, it is not necessarily a function of distancing or of avoiding blame, but of bolstering the credibility of that reported, indicating that which doctors do not know or have not done first hand, and that which reflects activities of a broader medical team and so on.

In *Extract 5.4* the doctor has just summarised that the surgeon performed the operation. He then begins to relay the findings of the operation, whilst paying particular attention to the patient's lymph node status. The extract is again lengthy, but I think the insights gleaned from longer strips of interaction are worth the inconvenience of (slightly cumbersome) longer fragments.

Extract 5.4 (Case 2.)

01	Dr:	AND he removed ↑ten ↓lymph nodes which were at↑tached (.)
02		to the bowel.
03	Pt:	right
04	Dr:	.hhh and none of those ten lymph nodes had (.) cancer (.) in
05		them
06	Pt:	oh right=
07	Dr:	=al↑right=
08	Pt:	=right
09		(1.0)
10	Dr:	<HOW↑ever> one of those cancer cells- er one of (.) those
11		lymph nodes had some cancer >clo::se< to i↑t:
12	Pt:	right
13		(0.5)
14	Dr:	it was an un↑u::sual situation. I'll try and explain it <the best I
15		can> as to what it was
16	Pt:	yep
17	Dr:	.hh the ↑reason we take lymph nodes ↓out (.) is that the ↑lymph
18		nodes are <sort-of> the first port of call: <if you like>=
19	Pt:	=ye:es
20	Dr:	↑if any cancer cells are going to go elsew[here.

21 Pt: [°that's right (to other
22 or↑gans and)°=
23 Dr: =AND **we've** looked <u>into</u> the ↓lymph nodes to see if any cancer
24 cells have settled (.) ↓<u>in</u> those lymph nodes
25 (0.3)
26 Dr: and in ONE of the lymph nodes (.) there was some cancer cells
27 go↑ing (.) ↓close to that lymph ↓node
28 Pt: right=
29 Dr: =but they hadn't actually ↓<u>settled</u> in there
30 (.)
31 Dr: al↓right
32 Pt: ( )
33 Dr: ↑NOW (.) >be↑c<ause of ↓that **we can't say** (.) that there
34 definitely were cancer cells ↓ther[e]
35 Pt: [no]
36 Dr: but obviously (.) seen as those the cancer cells were close (.) ↑to
37 ↓i:t=
38 Pt: =then you'[ve (got to be cautious)
39 Dr: [RAISEs that sort of sus[picion.
40 Pt: [<↑yeph ↓yeph>
38 (1.0)
39 ((The doctor continues to explain that the upshot of suspicion is
40 that the patient should have chemotherapy))

In this fragment, the doctor produces himself as one doctor of many and this *does work*; it renders the information 'objective' and not just the opinion of one doctor. That is, the doctor builds a story that is collegial in nature, but not necessarily distanced from the individual doctor in the here and now. For example, the doctor's pronoun use discursively invokes the authority of medical knowledge or 'collegial authority' (Strong, 1979)[9]; '*he* removed ten lymph nodes' (1), 'the reason *we* take lymph nodes' (17), '*we've* looked into the lymph nodes' (23), '*we* can't say that there definitely were cancer cells there' (33-34). The use of 'we' or 'I' "bolstered" by 'we'

[9] Strong's (1979) examination of the 'ceremonial' aspects of meetings between patients and doctors introduced the notion of 'collegial authority'. In particular, Strong related this to health professionals' expertise and its accomplishment. He states thus: "...this expertise had a 'collegial' rather than an individual character. Doctors were expert because they belonged to an expert profession... all with equal access to a standard body of medical knowledge" (pp70-71). We will see that although the call of 'collegial authority' is invoked through the voices used, in different emphasis to Strong, the very act of calling forth the evidence leads to doctors demonstrating their expertise or that of their colleagues, rather than them simply relying on an assumed authority.

can, depending on the task in hand, discursively invoke a 'persuasion form of consultation', where 'we' "is the voice of the medical team" (Silverman, 1987). Here, the evidential citation appears to be situated in 'fact' and not based on an individual opinion. Consider *Extracts 5.5, 5.6* and *5.7.*

Extract 5.5 (Case 4.)

01	Dr	there's no evidence of spread elsewhere at the ↓mo↑ment (.) but
02		what **we** ↑do to work out what that risk is, and whether or not **we**
03		should think about chemotherapy treatment, IS that **we** (.) look at
04		what (.) the cancer **looked** like under the microscope=
05	Pt	=yeah=
06	Dr	=alright? hhh and **we** look at various different things under the
07		microscope. if **I** can go through what **we** l-look at and then
08		explain (.) how **we** come to our (.) con↓clusion=
09	Pt	=yeah=

In much the same way as in *Extract 5.4,* during the evidential explication, through the use of 'we' the doctor achieves an air of collegiality. For example, "what **we** ↑do to work out what that risk" (2), "if **I** can go through what **we** l-look at and then explain (.) how **we** come to our (.) con↓clusion=" (7-8) and so on. In other words, the doctor's footing in the delivery of the information sets him up as one expert among many. As in the other extracts, the doctor proceeds to produce the rationale for treatment (not shown), based on the explication of the diagnostic evidence.

In line with Peräkylä's (1998) observations, the provision of evidence in and of itself produces the doctor's actions, in particular the disposal for further treatment, as morally defensible; he is in the business of administering chemotherapy and so to avoid the criticism of unnecessarily pursuing a treatment line, he provides the basis on which his (and other doctors') decisions have been made[10]. I return to this point a little later.

In *Extract 5.6,* the doctor's 'footing' again positions him as a member of a broader medical team.

[10] The doctors have usually however already reached a treatment disposal during multi-disciplinary meetings and it would take some work for the patient to reject the proposal to treat.

Extract 5.6 (Case 5.)

01	Dr	>and< (.) what-(.) what the **pathologists** have ↑told us is that (.)
02		<well> **we** ↑knew there was a small cancer in the ↓bre↑[ast
03	Pt	[yes
		((lines omitted))
13	Dr	= ↓yourself (.) um (.) and (0.2) it h (hh)↑and a sort of o:↓r:↓dinary
14		<sort of averagy> appearance under the micro↑scope (.) **pathologists**
15		look at the ↑**picture** of the ↓cells
16	Pt	yes=
17	Dr	=and **they** score it [one] two or ↓three
18	Pt	[cough]
19	3rd	°right° oh ↑I see ↓right
20	Dr	and you got- scored ↓two

The doctor narrates the pathologist into his evidential citation and positions him / her as a central actor in the patient's case management, ">and< (.) what-(.) what the pathologist has ↑told us" (1), "pathologists look at the ↑picture of the ↓cells" (14-15), and "=and they score it [one] two or ↓three" (17). In so doing, the doctor tells the patient that he is one doctor of many, or the co-ordinator or captain of a team, and hence he bolsters the objectivity of the information delivered and introduces a scientific technicality. The doctor's agency in relation to the information skilfully conveys some measure of objectivity, whilst also allowing him to establish his position in relation to a consequent disposal to treat further.

The voice of 'we' can also be used to recommend a potential no-treatment line. In *Extract 5.7,* the consultation takes place with a man with advanced stage bowel cancer. The doctor and patient are faced with the unenviable position of having to discuss hypotheticals because of a query over spread of the cancer to the liver. Consequentially, two alternative treatment scenarios are raised and the potential for chemotherapy to cure the patient in either scenario - spread or no spread - is quite different, with the latter scenario meaning probable non-cure / no remission, and a short survival span.

Extract 5.7 (Case 6.)

01	Dr:	if↑ I was see↓ing you and there was no evidence at operation
02		of spread ↓to ↓the li↑ver=
03	Pt:	=um=
04	Dr:	=then I would be saying I would get a C↑T scan (.) to check
05		that there was no evidence of [spread
06	Pt:	[yes
07	Dr:	and in somebody like yourself who is ↑FIT with a Duke ↑C
08		cancer of the bowel I would recommend chemotherapy
09		treatment=
10	Pt:	=yes=
11	Dr:	=the REAson for that is that we kn:ow in patients with Duke's
12		↑C cancers of the bowel (.) there is quite a ↑high risk of
13		developing recurrence of the disease o↑ften elsewhere=
14	Pt:	=yes
15		(2.0)
16	Dr:	probably in the order of 60-70%=
17	Pt:	=(as high as that)=
18	Dr:	=yes
19		(2.0)
20	Dr:	AND we kn::ow that chemo↓therapy reduces that risk
21		(1.0)
22	Dr:	<by about a third>
23	Pt:	(mm)
24	Dr:	and has been shown to improve survival=
25	Pt:	=yeph=
26	Dr:	=as well (.) so I would be therefore recommending
27		chemotherapy treatment because of that=
28	Pt:	=certainly
29		(3.0)

Above the doctor's talk traverses different production formats or footings. He moves from the voice of I through to the voice of we. He opens up the sequence about treatment with the hypothetical statement, "if↑ I was see↓ing you and there was no evidence at operation of spread ↓to ↓the li↑ver=" (1-2), to which the patient responds with the minimal continuer "=um=" (3). The doctor proceeds to embellish what his actions and treatment disposal would be in the voice of 'I', "I would be saying I would get a C↑T scan (.) to check that there was no evidence of [spread" (4-5).

It is routinely the case that future anticipated organisation and management of a patient's case is reported in the voice 'I' and, by contrast, the evidence for that management, in this case diagnostic evidence and the evidence for a particular treatment disposal, is first of all stated in the voice of 'we'. In other words, once the evidence is 'out there' as credibly grounded evidence, doctors then tend to speak in first person. In this way, we can see that doctors may bolster their own future actions with recourse to a footing that invokes the voice of collegial authority (Silverman, 1987). On a rare occasion, when this order is not apparent, doctors still seek to nest their claim, opinion or position in some relevant and collegially based evidence[11].

Returning to *Extract 5.7*, following an overlapped 'yes' receipt (6), the doctor tells the patient that in *anybody* like him he would recommend chemotherapy, "and in somebody like yourself who is ↑FIT with a Duke ↑C cancer of the bowel **I** would recommend chemotherapy treatment=" (7-8). Notice here that the voice of 'I' is used again, but only once the disposal has been produced. The doctor then moves to the voice of 'we' to bolster his recommendation, =the REAson for that is that **we** kn:ow in patients with Duke's ↑C2" (11-12), "AND **we** kn::ow that chemo↓therapy reduces that risk" (20-21)[12].

The doctor restates his disposal for chemotherapy and proceeds to inform the patient that *if* there is spread to the liver he would still recommend chemotherapy but the result might not be cure (not shown). In this *Extract,* the doctor vacillates between the voice of 'I' and 'we', where the latter works to "bolster" the former. In short, the rationale for the doctor's (hypothetical) recommendations is firmly grounded in a wider knowledge base, the authority of medicine and other medical professionals.

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[11] Case A.
Dr: so: if the lymph nodes were not involved **people** could sort of argue do you need chemotherapy or do you not need chemotherapy °treatment° but **I** ↑think (.) in this situation whe::re (.) the lymph nodes ↑have been shown to be involved (.) there is no question that you should have chemotherapy treatment
Pt: (I agree) right (.)
Dr: the ↑REASON I say that (0.2) <so: sort of> dogmatically is that it's been shown (.) t- from studies with ↑thousands of patients (.) ((Continues to give evidence))

[12] This relation between the voices of 'I' and 'We' is similar to that found by Wilkinson and Kitzinger (2000) in focus groups conducted with breast cancer patients. Individual focus group participants bolstered their viewpoints by raising the synergy between their view and those of others. Recourse to 'different voices' is a resource that all members have available to them and may use when giving evidence, advice or opinions.

Let us consider a few shorter extracts, where the doctors accomplish a form of collegial authority during their evidential citation. In *Extract 5.8,* the doctor uses the voice of 'we' when discussing general processes of the medical assessment of risk.

Extract 5.8 (Case 1.)

01 Dr the ↑things **we** look at are what >s:↓ize< the cancer is
02 what it looks like if there's any growth into↓blood
03 ves↑sels ...

Again, the doctor neatly tells the patient that it is not just him as the doctor in the here-and-now who is involved in her particular case but he is part of a broader institutionalised order which has general methods of 'doing things', including the assessment of risk, based in this case on a method of viewing the pathology. The doctor hearably avoids casting himself as a doctor who relies solely on his individual opinion alone, but instead one who is part of an established tradition in which he plays a role.

Extracts 5.9 and *5.10* show further how the voice of 'we' can be used to outline the treatment disposal once the evidence has been explicated.

Extract 5.9 (Case 7.)

01 Dr: and for ↑that reason **we** recommend some f:ur↓ther
02 (.) ↓treatment (.) <↑**we**> (0.1) it's still a
03 pre↓cautionary ( )- (.) **we** ↑MAy ↓not need it

Extract 5.10 (Case 1.)

01 Dr: =and: (.) explain <therefore> why **we'd** ↑like (.)
02 <why **we** think you should have chemotherapy
03 treatment> I'll then explain what the
04 chemotherapy in↓volves
05 (.) al↑right

In *Extract 5.9* and *5.10* the voice of 'we' hearably highlights activities undertaken by the medical team in dealing with these patients' specific cases. The use of 'we' produces the treatment disposal as arising out of the decision-making activities of the broader medical team.

As suggested, 'we' appears to be the 'voice' of evidence and decision-making contextualised in that evidence, whilst the voice of 'I' figures more strongly for future actions "I will organise chemotherapy", "I think it best if we get started soon", "... and because of that evidence I would recommend chemotherapy".

It is clear that there are differences in the use of "we" in the course of different sorts of activity. Sometimes general processes of medical work are reported, whilst at others activities undertaken in relation to particular patients are described via 'we'. On all occasions the use of we bolsters the credibility of that being described.

Moving away from the 'voices' used in these fragments for a moment to make a general note. *Extracts 5.4 – 5.10* suggest another recurrent feature common to doctors' evidential citation. Their stepwise presentation of evidence is similar to that found in scientific papers (Hyland, 1998). First, often via agenda forecasts, the aims and scope are established, in the context of the shared knowledge of cancer (background), the diagnosis is embellished and the continued risk outlined (akin to the results). And, finally, the implications of the diagnosis are related to a treatment disposal (akin to conclusions). It is worth noting that lay-audiences, such as patients, are not the standard recipients of such 'scientific papers' or expositions and as such how this relationship and information exchange is managed is crucial. Moreover, the information proffered is not usually so intimately tied to the (reading) audience. Patient recipiency is discussed in the next chapter (*Six*).

Doctors' footing throughout the evidential explication situates them as reporters of others' knowledge ('we'), whilst still conveying expert status by being in the position to report on that knowledge ('we' or 'I' bolstered by 'we), understand it and take 'appropriate' action in light of it ('I'). Silverman (1987) notes the use of the voice of 'we' and 'I' in hospital consultations with parents of children with congenital heart problems.

> The voice of 'I' receives support from its institutional base but also reveals its authority in being able to formulate its proper action – exactly what 'we should do'. This combination of authoritative reflection and collective action reveals the power of the persuasive mode.
>
> Silverman, 1987: p57.

Silverman (1987) also notes that the patency of a condition can diminish the requirement of a "persuasion format". However, despite the patency of many of the cancer cases dealt with in the data corpus, doctors still seek to contextualise and legitimise the recommendation for further treatment. Similarly, it has been proposed that the logical stepwise progression through the constitutive elements of the information provided also *does work*. Maynard (2003) suggests:

> Reciting the evidence and being logical, accordingly, appear as practices that deflect the issue of a deliverer's responsibility.
>
> Maynard: p214.

Whilst tempting solely to view the talk found here as *neutral* (Clayman, 1992) and as 'deflecting the information provider's responsibility', it seems rather that it (also) signifies the deliverer's orientation to a responsibility to make accessible and transparent the different bases on which medical disposals are founded. Over twenty years ago in a discussion of the various ways conversationalists tell 'how I know', Pomerantz (1984a) pointed out, "...the sources or bases may be offered to provide recipients a way to determine for themselves the validity of assertions" (p624). In similar vein, it might be then that the moments analysed in this chapter are about actions that 'give information', whilst allowing patients to 'determine for themselves the validity of the assertions' made about diagnosis and treatment. Following Peräkylä (1998), diagnostic explication in and of itself may be one example of how *doctors-do-being-accountable.*

Contra Maynard's (2003) observations, it is also possible to view doctors as orienting to a responsibility to contextualize the information delivered in a broader medical context. The persuasiveness of the arguments proposed by doctors may, of course, be enhanced through recourse to differing voices[13]. But, this does not equate to 'eviscerating the doctor's individual responsibility' in the here and now of the

[13] In his work on doctor-doctor talk, Atkinson (1999) found that, "the Fellow's presentation includes narrative elements in which are inscribed the temporal and organizational distribution of prior and current work. The Fellow is at pains to report what others are doing or are reported to have done" (p97). Thus, rather than the giving of evidence and giving in certain ways being about 'duping' patients into believing the credibility of the information provided it might well reflect a strategy that members in many contexts use to 'share' the responsibility and to accountably provide the source of the information being "animated".

consultation. Doctors do not labour the point of objectivity, but imply it through recourse to different 'voices' and the expertise implied therein.

One must also ask what are the alternatives? How else can doctors make transparent the processes engaged to reach a point where a diagnosis and treatment disposal has been reached? It would be difficult to engage the voice of 'I' whilst reciting broader activities of the medical assessment of risk or other activities undertaken by the medical team. Doctors in the here and now are part of a 'we' and as such they animate news and activities that are authored or undertaken by others at other moments on the patient's care pathway.

That this method enhances credibility does, of course, serve an important function in these meetings. As already stated, patients should have already received some treatment, in the form of surgery and / or hormone therapy and for them to undergo a further treatment is a potentially worrying journey to voluntarily embark upon. In other words, there needs to be a sound, understandable and explicable rationale for having radiotherapy and chemotherapy. Herein again lies the fascinating practical problem for the doctor – how to demonstrate the success of the prior treatment, whilst still encouraging further treatment. Getting patients to realize the benefits and the credibility of a treatment recommendation is key. This, when coupled with the concern to engage patients and to accomplish some version of 'patient-centred' care is critical. Here we see how doctors attempt to demonstrate the credibility and benefits of treatment, whilst the actual act of calling forth the evidential basis for such claims enhances the opportunity for some user involvement.

Doctors' appeals to a broader knowledge base and experience of similar situations is an important part of how the treatment is set up as a reasonable course of action for patients to follow *with* their doctors. Moreover, the detail with which diagnoses are embellished fits with and possibly reflects the 'complex' nature of cancer as a disease. Following on from this, I want to shift tack slightly to consider the level of detailed explication in the oncology spaces dealt with in this thesis, especially when compared to the lower level found in some primary care settings explored by authors like Heath (1992) and Peräkylä (1998). Here I take Peräkylä's (1998) work as an example to develop this comparison.

5.4.1 Peräkylä's primary care meetings and outpatient oncology

We have seen that the way in which information is produced invokes the 'voice of medicine' and that this accords the information an objective quality. Indeed, the analogy of the recitation of evidence in a scientific paper illustrates this clearly (Hyland, 1998). Given these characteristics it may be argued that the 'power of medicine' and more specifically doctors' authority is talked into being, and in quite strong terms. The corollary of this may be a relatively *disempowered lay voice* or a subordinate role for patients. Doubtless there is some validity in this line of argument; I turn briefly to the institutional features of the talk-in-interaction in the Discussion (*Chapter Seven*). However, this mono-consequential interpretation of *dysfunction* belies some important *functions* of the work accomplished.

Peräkylä (1998) examined over 100 medical consultations, drawn from four health centres and 14 doctors, with a different patient involved in each consultation. He made a collection of diagnostic statements (N=71) to analyse and develop a typology of practices of referring to evidence in the delivery of diagnosis. Peräkylä's (1998) examination suggests that the very act of providing evidence can mean that doctors are not solely relying on their authority as medical professionals. By contrast, in providing the evidential basis for decisions or recommendations, doctors orient to their accountability. As briefly outlined in the Introduction (*Chapter One*), in Peräkylä's data we see three designs of diagnostic utterances. He describes these as follows:

1) Plain assertions: doctors state the name of the illness "it is X".
2) Turns incorporating inexplicit references to the evidence: doctors use "evidential verb constructions such as "it seems to be X"".
3) Turns that explicate the evidence: doctors describe specific observations as evidence for the diagnostic statement.

Peräkylä's examination of primary care meetings shows that the "home base" communicative frame is one of "plain-assertion" (1), such as, "that's arthritis" or "that's a throat infection". By contrast, in the outpatient consultations analysed here it should be clear that the diagnostic evidence is explicated in some detail, in more

elaborate fashion. For example, nowhere in the corpus do we see an equivalent approach to 'plain assertion' where, for example, doctors produce the diagnosis, "you have cancer, with lymph node involvement" rapidly followed by, "so therefore we recommended radiotherapy". Rather, the diagnostic details are spelt out, as is the future risk and the consequent treatment implications. Doctors generally explain what lymph nodes are, that their involvement may result in an elevated risk of spread or recurrence elsewhere and, only after a detailed citation of the evidence, do they move to the management of the patient's particular complaint by raising the treatment disposal. In so doing, in more pronounced terms, yet in similar vein to the doctors examined by Peräkylä, we see oncologists 'balancing their (claims to) authority with their accountability for their actions'.

In contrast to Peräkylä's (1998) home base format of "plain assertion", here we have a 'home base format' of 'direct explication'. That the "plain assertion" format is not found in the space of the oncology consultation is unsurprising if, for a moment, we again consider the differences in the conditions being dealt with in each space. There are over 300 different kinds of cancer and it is a complex condition, much more so than many (of course, not all,) of the conditions managed in primary care. Diagnosis is complex and, relatedly, the type of treatment required can be complicated. Cancer is (constructed as) multi-stage, with complex aetiology and so forth and hence the treatment requirements vary from person to person. This is patent in later moments in the consultation when doctors move to describe the different types of chemotherapy available and detail their relative strengths for x, y or z type cancer (not shown).

Speculatively, if doctors did not explicate the diagnosis, the different types of therapy available would be (more) difficult for doctors to describe in patient-relevant terms and more difficult for patients to grapple with, without such background diagnostic information. Conversely, by providing such detailed information, doctors may be criticised for being too heavily "wedded to their own agendas" (Pilnick, 2002). However, similar to Pilnick's (2002) genetic counsellors, allowing clients / patients to set the agenda may be unachievable. Clients / cancer patients might not "know what will be considered relevant in a particular situation" or might not have "sufficient background knowledge to formulate appropriate questions" (p85). The meetings analysed here are heavily focused on providing 'background knowledge' and,

speculatively, later in the patient trajectory we might see more *active* patient information gathering and question asking, which in turn help to form the foundations for ongoing decisions around treatment. The practical problem that arises then is how much (detail) to tell, when and how.

Further, that we see a different texture and depth of evidential citation in these meetings rings true when some of the broader issues of disease type and disease management are considered. Doctors underscore their status as *specialists-working-in-a-hospital*, which is likely to be their patients' final port of call; the final stage of treatment and post treatment follow up. They are unlikely to be referred elsewhere, as in a GP consultation. In other words the doctors in the meetings examined here are *doing being specialists*. Indeed, Peräkylä (1998) raised the requirement for caution when interpreting his examination of primary care consultations by stating, "practices of referring to evidence may be different in other medical contexts such as specialized or hospital medicine" (p304). Differences aside, there are similarities in the organisation of information. Following his (2002) examination of Finnish primary care meetings, Peräkylä reflects:

> Doctors display to their patients the evidence on which their diagnoses are based...In terms of the social relation between the patient and the doctor, there is something other than mere authority involved in the delivery of the diagnosis...The doctors treat themselves as accountable for the evidential basis of the diagnosis, thereby not claiming unconditional authority vis-à-vis the patients.
>
> Peräkylä, 2002: p221

The evidential citation not only orients to doctors accountability but it works to cast patients as "theoretic agents". That is, individuals who are capable of being persuaded by evidence, understanding it and making *appropriate* decisions grounded in the information shared (Silverman, 1987). Clearly, the question of patient understanding of the evidence provided, or more generally how they treat the evidential citation, is an important one. In *Chapter Six*, I show some of the ways in which patients can and do treat the information provided.

5.5 Discussion

In this final section I want to review the relevance of giving evidence, the relevance of the different 'voice' or production formats and provide a few concluding remarks on the general importance of that covered in this *Chapter Five.*

5.5.1 The relevance of giving evidence

In *Chapter One* (Introduction) and *Chapter Two* (Natural History), I introduced the existence of a large literature that reports on a vast and recurrent asymmetry between doctors and patients in the kind of medical meetings analysed here. I suggested that much of this work classifies medical practice as *routinely* asymmetrical, without demonstrating how this is so. Moreover, I proposed that to focus on asymmetry as an intrinsic *evil* minimises the opportunity to note how participants work with the often-inevitable 'knowledge' differences.

We have seen how asymmetry is undoubtedly a feature of the cancer consultation. This is particularly the case when we look at who has topical control, who sets and pursues the overall agenda and (not exhaustively), who is in possession of the information necessary to embellish the cancer diagnosis and discuss the consequent treatment options in institutionally relevant ways. Doctors' claims of knowing that there is a risk because of what the cancer looked like under the microscope, for example, cannot easily be contested by those to whom the news relates most intimately. However, this chapter has shown *how* this lay-expert divide is managed and how certain approaches to information sharing can soften (the sometimes inevitable) asymmetry.

The ideal of user initiated agendas, one form of patient centred care, was shown to be problematic in practice in Pilnick's (2002) conversation analytic study of genetic counselling consultations. As discussed, when counsellors pursued the route of allowing clients to initiate the agenda, patients floundered to do so; they struggled with the relevance of their thoughts to the goal of a genetic counselling session. One possibly more realisable 'asymmetry softener' in the outpatient oncology

consultations, which clearly has a broader project or agenda, is the very act of diagnostic elaboration.

The evidential explication means that doctors do not rely solely on the authority bestowed by the identity or category label *specialist cancer doctor*. Rather, "orientation to authority is counterbalanced by their orientation to the doctor's accountability for the evidential basis of the diagnosis" (Peräkylä, 1998: p304). In short, "by displaying evidence, the doctor earns his claim to knowledge".

Establishing that doctors give evidence in the cancer consultation and that differences are observable between the ways 'evidence' is given when compared with primary medical care meetings is important. The volume of information and level of detail provided contrasts with that generally found in primary care meetings and, as already noted, it is perhaps unsurprising that such differences are observable. Peräkylä's observations of the contrasting cases or "departures" from the 'home base' of "plain assertion" resonate with the work performed in outpatient oncology; "the observability of the evidential grounds for the diagnosis" is apparent or made apparent to patients (1998: p309).

This format occurred in Peräkylä's data when, for example, a doctor delivered a diagnosis some time after an examination, when s/he would "often take special measures to make the grounds of the diagnosis observable by incorporating references to those grounds into the turn or by explicating them" (ibid: p309). The 'inferential distance' between the diagnostic embellishments in the meetings detailed in this thesis and the grounds for diagnosis and treatment is vast. Moreover, cancer is rarely visible, indeed many cancer patients report "feeling fine" prior to diagnosis (Leydon et al., 2001). The importance of explication is brought even sharper into focus in these cases, especially where further treatment is required.

Further grounds for detailed explication also arises from Peräkylä's (1998) work. He notes that detailed information delivery most often occurs in general practice when, "the doctor's expertise becomes problematic because of uncertainty or disagreement" (1998: p312). Where uncertainty and diagnostic complexity featured, doctors' turn designs would be more complex. In other words, uncertainty and accountability are

intertwined and "uncertainty undermines the doctor's authority as an expert" (ibid: p314). Since the "devil of uncertainty" rears its head time again in cancer, doctors' work hard to explain that which they do know, alongside that which they do not know first hand or cannot ever *know*[14]. We will see this clearly in the next chapter (*Six*).

There are other practical reasons for the "home base" format differences between primary and secondary care meetings, which will not be considered in any detail here, but these include medico-legal reasons, the need for informed consent to treatment, severity of the illness when compared with those routinely managed or diagnosed in general practice, and patient expectations about the management of their complaint. Indeed, in terms of 'patient expectations', the detail delivered positions doctors as experts or specialists, as opposed to generalists. Rather than this approach to information delivery representing a dysfunctional asymmetry, it is possible that such displays of knowledge may be received as reassuring by patients and may (begin to) facilitate the requirements of informed consent for treatment and 'shared' decision-making. Doctors accord patients a "theoretic capacity", capable of understanding medical information (see Silverman, 1987: p30; Strong, 1979)[15]. In the meetings there is little evidence of 'shared decision making', but the foundations for decision-making are provided. These may make 'shared decision making' possible at later stages in the patient trajectory. Indeed, as noted, there is some evidence that patients become more 'active' participants in decision-making as time moves on (Silverman, 1987).

[14] I do not wish to overplay this as a potential 'explanation' however. It is difficult to claim that greater uncertainty exists and hence greater explication occurs. To do so suggests a neat causal relationship and begins to posit that uncertainty exists 'out there' somewhere, external to the interactively achieved uncertainty. How do we 'know' that a medical issue is 'complex' other than through how it is talked about?

[15] "Strong found that doctors portrayed parents as moral, rational and intelligent. Parents were treated, therefore, as people with whom a rational discussion about the condition and its treatment could take place. Parents were addressed as theoretic actors, able to understand choices and able to be persuaded by evidence – once they knew the facts... Our observation of more than 1000 outpatient encounters wholly accords with Strong's findings about the appeal to reason and politeness" (Silverman, 1987: p30).

5.5.2 The relevance of voices

> In professional settings, like ordinary conversation, bearers of news are not just the conduits of information; their own agency can figure heavily in the interaction and moral discourse surrounding the news.
>
> Maynard, 2003: p225.

To recap briefly, Peräkylä (1998) focussed on the coordination of the design and placement of the diagnosis in relation to the examination of the patient and the telling of the upshot of that examination. Here we add to Peräkylä's observation by focusing on the voices used during the diagnostic explication and the move to treatment talk.

Doctors' use of 'we' seems to enhance the credibility of the diagnostic evidence provided and the treatment proposed. Particular voices can work to inform recipients to the information that it is not just one doctor's view being noted, but also that of others, and other experts (see Lepper, 2000: p 40). Shifts in footing (e.g. "'we' think you need treatment", "the 'surgeon' removed the cancer", "'we'll' keep an eye on you", "'I' think we can be hopeful, histology shows no signs of spread") aid the accomplishment of a collegial footing and doctors make their treatment proposals in that broader context. Maynard's (2003) point that such a format makes it more difficult for the recipient of the news to 'shoot the messenger' is undoubtedly well grounded. The utility of *voices* for health professionals[16] probably resides in the knowledge that:

> The number of persons aligned with any given statement can be seen as an index of its facticity...a widely endorsed viewpoint is not easily dismissed...
>
> Clayman, 1992: p189.

Enhancing the facticity or credibility of that reported may then minimise recipients' opportunities for contesting the information shared, but other players *are* involved in arriving at 'viewpoints' and doctors make these other players known. The alternative is unclear and the functionality of various footings will vary according to the

[16] This is not to suggest that 'voices' are just a feature of institutional talk. All members resort to different voices in everyday life. For example, Gubrium (1986) has shown how Alzheimer's spouses explicitly cite a voice e.g. "speaking as a wife".

participants and the setting. Neutrality, for example, may have a more central function for news interviewers when compared to the doctors found in this study. On the other hand, objectivity, in the 'scientific' sense, and the call of collegial authority to bolster the facticity of any given statement is hearably and observably of concern in the oncology meetings considered here.

5.5.3 A summary

Doctors are charged with the responsibility to work within policy frameworks and the relevant standards set. Their major challenge is to ensure user involvement, whilst explicating information that lay members cannot be expected to know or even fully understand. More specifically, in the meetings considered here, doctors need to demonstrate the success of prior treatments whilst still producing radiotherapy or chemotherapy as a reasonable next step. In this chapter we have seen how doctors grapple with these challenges.

In the next and final data chapter (*Six*), we see how the diagnostic and treatment talk proceeds and how a context of uncertainty is invoked when doctors provide relatively good and bad information about the potential for treatment to impact upon the cancer; of what it *might* and *might not* achieve in the light of the individual patient's diagnostic profile. Analysis shows that an important feature of how the participants achieve this treatment talk is by establishing and sustaining a *positive frame*. This positive frame appears to take the 'sting' out of the news being delivered and creates a solidary and ripe environment for the ongoing sharing of relatively 'good', 'bad' and 'uncertain' information.

6.

Negotiating the relative good, the bad and the uncertain

> However "radical" the surgical intervention, however many "scans" are taken of the body landscape, most remissions are temporary; the prospects are that "tumour invasion" will continue or that rogue cells will eventually re-group and mount a new assault on the organism.
>
> Sontag, 2001: p64-5.

6.1 Introduction

In the same fashion as previous chapters, this chapter picks up from where the previous chapter left off. This is done with a view to (as far as possible) tracing the logical progression through tasks and hence providing a view of (part of) the trajectory of the cancer consultation. In *Chapter Five,* the activities of diagnostic embellishment and the stepwise move towards the doctor's treatment disposal were examined. In this Chapter, we see that once doctors and patients have established the diagnosis and contextualized it in terms of the treatment available to them and the evidential benefits of that treatment, doctors directly topicalize or indirectly orient to the *uncertainty* of cancer and its treatment.

This chapter develops previous treatments of good and bad news deliveries (and receipts) to show how (once patient diagnoses are embellished and, in light of that, the treatment options explained) doctors orient to the 'uncertainty' of cancer with patterned regularity. Such an orientation is both in terms of cancer as a disease, "cancer being cancer one can never be sure", and in terms of the treatment of cancer, "there are no guarantees, but we hope radiotherapy will work".

There is a potential negativity inherent in presenting the possible threats to current and future health once the treatment disposal has been announced and agreed, especially in the context of medical meetings with patients who may be presumed to be experiencing some kind of "noetic" crisis in light of their cancer diagnosis (see Maynard, 2003). In particular, the underlying tension between these different forms of information and the various ways in which information can be framed has the inherent potential for dilemmas to arise between, for example, presenting a balanced view of uncertainty vs. opportunity or realism vs. optimism and these have been attended to in the social scientific literature (e.g. Sontag, 2001; Beardsley, 1994; Giddens, 1991, Green, 1997, The, 2002, Costain-Shou and Hewison, 1999, Beach, 2003). The ontological insecurity produced in and through the infinite array of risks and the presumed certainty of death or increased risk of 'early' death when cancer is diagnosed has been explored. This has occasioned a body of work that provides for an understanding of the complex interplay between such things as risk, hope, threat, knowledge, and cancer (e.g. Burkitt-Wright et al., 2004; Brewin, 1977, 1985; Candlin and Candlin, 2002; Chalmers and Thomson, 1996; Leydon et al., 2000a,b).

The work of Beach (2001; 2003), Maynard (2003) and Maynard and Frankel (2003) is central to the examination provided here. These are some of the few to have moved beyond patient and doctor reports of these phenomena to examine the actual process of communicating good and bad (in the context of uncertainty)[1]. Indeed, as Lauritzen and Sachs (2001) suggest, our understanding of how medical uncertainty is relayed, socially occasioned, achieved or comes to have meaning in interaction is "quite imperfect". The practicalities of how this kind of work can be achieved whilst maintaining 'expertise' and 'hope' are continuing to interest academics and practitioners alike; evidenced recently in a comment made by the editor of the BMJ.

> And—a question that interests me—how do you share the uncertainty that is ubiquitous in medicine and still seem to have expertise?
>
> Smith, 2004.

[1] Obviously a great deal of work has focused on the 'bad news' interview, but as Ptacek and Eberhardt's (1996) systematic review lead them to conclude, "Although much has been written on the topic of breaking bad news, the literature is in need of empirical work".

6.2 Organisation of this chapter

In *Section 6.3*, I examine the relationship between relatively good and bad information and how each is delivered. In particular, I inspect some of the ways in which information is organised to protect patients and doctors from consultations that become overwhelmed by (relatively) bad news. Analysis builds on previous work on good and bad news by also showing the recurrent orientation to that which is 'uncertain'. The potential negativity of uncertainty is hearably and recurrently offset or balanced by doctors' recourse to a *positive framing* of the information shared[2].

In *Section 6.4*, patient uptake of information delivered is considered. On rare occasions the valence of news may be ascribed in quite strong terms by patients, third parties or doctors. Overall, throughout the corpus there is a general tendency to establish and maintain a positive frame, but patient upset may sometimes overshadow this.

6.3 Some organizational features of the good, the bad and the uncertain: News deliveries

> Being 'in the cancer journey'... involves numerous courses of action marked by shifting mixtures of good and bad news that must be addressed simultaneously.
>
> Beach, 2001: p241

In this *Section* I consider the general preference for an *optimistic* framing whilst producing news that may be classified as good, bad (or uncertain). This is accomplished via two key organisations. These are referred to as the 'pairing phenomenon' (*Section 6.3.1*) and the 'power of proximateness' (*Section 6.3.2*).

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[2] As an aside, and as already discussed in *Chapters One* and *Two*, full and frank information sharing is broadly recommended in practice guidelines to assist patients with informed decision-making and to ensure patient participation. Open and detailed information delivery presents a number of challenges or double binds. For example, while observing the clinic one day an information radiographer once noted how difficult it is to have to tell patients about all of the potential negative side effects of treatment, such as a 1% chance of cracked ribs from radiotherapy. She felt that such information had little impact on patient decision-making and wondered instead whether it caused potential anxieties about effects that are highly unlikely to happen. In short, she wondered who benefited from such disclosures.

6.3.1 Introducing the "pairing" phenomenon[3]

Extracts 6.1 and *6.2* below introduce the organisation of pairing (without transcription conventions). Following embellishment of the diagnosis of cancer of the tonsil and the doctor's recommendation for radiotherapy, the doctor introduces what he hopes radiotherapy might be able to achieve.

Extract 6.1 (Case 1.)

01. Dr: your voice is unlikely ever to be quite as it was before
02. but hopefully it will be better than it is now and almost back to normal

Extract 6.2 (Case 1.)

01. Dr: obviously we can't guarantee that it will work
02. but there's a very good chance that it will

In *Extract 6.1,* the doctor indirectly orients to the uncertainty of the patient's case by delivering the news that his "voice is *unlikely* ever to be quite as it was before" (1) (my emphasis). This 'indeterminate' statement about the patient's voice is followed by a relatively *good* news announcement, "but hopefully it will be better than it is now" (2). The latter component of the doctor's turn works to soften or mitigate the possibility that the patient's voice will never be the same. This organisation is also present in *Extract 6.2*, "obviously we can't guarantee that it will work" (1), hearably bad news, "but there's a very good chance that it will" (2), followed by hearably good news.

Maynard (2003) has discussed the "pairing" of good and bad news in detail, and he states that one will often (though not always) follow the other. Hence, he suggests that more authors ought to look at both kinds of news simultaneously and seek to understand the relationship of one type of news to the other. More generally, in a longitudinal study of telephone calls between members of a family whose mother had terminal lung cancer, Beach (2001) examined the management of an uncertain dying trajectory and, like Maynard (2003), he notes the close relation of good with bad. Both authors have, then, demonstrated such an interconnection with good and bad in both everyday and medical settings and its omni-relevant status (Beach, 2003: p190).

[3] Not to be confused with Sacks' adjacency-*pair* observations (e.g. 1992: Volume II, Part VIII, Spring, 1972, LC1: p523).

This suggests that a *pairing* approach to news may be an everyday resource available to lay and professional members alike. Indeed, Beach (2003) takes this relation further, by referring to the importance of 'hope' and 'optimism' in the face of negative news:

> Family members rely on hope and optimism as resources for dealing with and attempting to ease burdens arising from the often harsh and restrictive impositions of such illness circumstances.
>
> p189.

In these chemotherapy and radiotherapy meetings, the *pairing phenomenon* noted by Maynard (2003) is evident, and hence 'good' and 'bad' information is contiguously produced and managed and this appears to take the sting out of 'bad' news by softening it with some relative 'good'. So, for example, the news that "lymph nodes were involved", is often paired with, "all of those were removed", or the diagnostic summary statement, "you've had a cancer", is followed by, "and the cancer has been completely removed". The organisation of pairing permits (and makes possible) an optimistic frame.

In *Extracts 6.1* and *6.2*, the doctor's lexical choice also laminates a hopeful layer onto the news of what treatment is likely to achieve, "almost back to normal", "hopefully" and, "good chance" it will work. In formulating the news in this way what may be normatively and inherently *bad* news is placed within a (more) positive frame[4].

Let us consider another fragment, drawn from a meeting with a young woman with breast cancer. The patient's view on what has happened so far has been solicited via a perspective display invitation (Maynard, 1992), and the doctor follows the display with a modified formulation of events.

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[4] There is no real way of knowing what patients remember, but it would be interesting to examine retention of information from the consultation and the 'spin' that patients place on the information recalled. It is worth noting however, that Beach's (2003) finding of the central role of 'optimism' suggests that 'optimistic' messages from consultations may later play an important function. For example, "managing optimism" was "evident across an assortment of social actions" including "acknowledging the importance of medical personnel by relying on the medical protocol and treatment procedures" (p189). Indeed, as Beach states: "here in my analysis of the consultation we have seen how prior discussions... are employed to constantly shape and update understandings about what is going on" (p191). We also saw the central role of 'prior discussions' in the discussion of History Taking, when doctors and patients draw on 'prior discussions' to 'update and shape understandings'.

Extract 6.3 (Case 2.)

01	Dr:	what do you understand so far about why you are	
02		here what's been explained to you	
03	Pt:	>err↑ hhh I've got cancer (.) some of it is invasive	←a.
04		.hhh so (.) I have to (.) have chemotherapy<=	
05	Dr:	=mm hum	
06		(2.0)	
07	Pt:	°yeah that's it hhh°	
08	Dr:	okay I think I'll start from scratch	
09	Pt:	right	
10	Dr:	okay I think that might be easier	
11	Pt:	mmm hum=	
12	Dr:	=you >HA↑d cancer<=	←b.
13	Pt:	=°mm hum°=	
14	Dr:	=you've had an operation and you've had cancer	
15		in the breast=	
16	Pt:	=mm=	
17	Dr:	=the cancer's been >completely rem:o::ved<=	←c.
18	Pt:	=mm hu[m	
19	Dr:	[with the operation (.) .hhh ...	
		((Continues to embellish diagnosis))	

Following the patient's perspective display (←a.), the doctor moves to cast the patient's medical position in a relatively more favourable light than that cast by the patient's account of what she understands. The doctor accomplishes this through lexical choice, "=you >HA↑d cancer<=" (←b.), with the emphasis on cancer being in the past and it being, >completely rem:o::ved<= (←c.) with the operation. In addition, the slow pace and prosodic character of the turn emphasises the cancer being something in the past, "HA↑d" and ">completely rem:o::ved<". The doctor's turn hearably softens the *bad* news that cancer was found by pairing it with the relatively better news that it is in the *past* and has been *completely removed.* In other words, the doctor solicits a view and immediately seeks to correct the displayed view. In this case the patient's perspective that she still *has* cancer is replaced with the medical view of a patient who has had a cancer removed[5].

[5] Silverman (1987) found a similar "search and destroy" manoeuvre in his examination of decision-making in a range of paediatric cardiology clinic consultations. For example, when the symmetry between a doctor's disposal for inaction and a parent's fear of the patency of their child's condition

Generally, the practical pay off of gaining alignment in this way is the seeming facilitation of topic transition and the ability to proceed through the consultation, whilst also pursuing the preferred disposal. Indeed, overall the pairing phenomenon seems to *detoxify* the cancer talk. Lexical choice, prosody and pairing facilitate the accomplishment of a relatively positive frame. The sequential ordering of information also plays an important role.

6.3.2 *Introducing the 'power of proximateness'*

The *sequential ordering* of the *paired* information delivery (just described) is the second feature to warrant attention. This feature involves following what is normatively and hearably a bad news delivery, with hearably good or better news; e.g., "Obviously we can't guarantee that it will work" (bad), followed by, "but there's a very good chance that it will" (good). I will call this feature the 'power of proximateness'[6]. That is to say, doctors not only work to produce a positive frame through their *lexical* choice and the *pairing* of good with bad, but also by *ending* their news deliveries with the (relatively) positive information[7]. Maynard notes the presence of a particular order to news in casual and institutional settings and calls these "good news exits" (Maynard, 2003: p177).

The procedural relevance of this organisation lies in Sacks' (1992) demonstration that in conversation the next speaker routinely responds to the *last part* of the preceding utterance. Organising turns in this way can, therefore, enhance the opportunity for patients (and doctors) to focus on the latter component of any turn or sequence of turns, that is the relative *good.* This allows the positive to become sequentially salient.

Let us consider the deployment of these two organisations when doctors orient to uncertainty.

---

broke down, Silverman demonstrated how doctors sought out such concern and 'destroyed' it with a medicalised version.

[6] Thanks to P. Drew; personal correspondence.

[7] This is not to say, of course, that this is the only way that doctors deliver their news across all types of consultation, but that a recurrent feature of the oncology consultations I have available to me is the presence of this type of organization, at the pre-closing treatment talk sections considered here.

6.3.3 *Introducing uncertainty: A demonstration of the two organisations*

Once doctors have summarised the patient diagnosis, and the treatment possibilities have been raised, doctors demonstrably work to ensure that the treatment disposal is contextualised within the uncertainty that surrounds cancer and its treatment. At a time when certainty (McKenzie, 1998) is often craved during these times of 'noetic' crisis (Maynard, 2003: p12), implying or directly orienting to the uncertainty of a patient's case potentially has interactional consequences. First, it (re)-presents possible *bad* news for the patient; the ramifications of orienting to risk and uncertainty can be considerable:

> Our increasing understanding of the risk we face does nothing to allay anxiety. Rather, anxiety increases, for there are 'few things that are certain in this uncertain and complex world', and the range of risks to manage is potentially infinite
>
> Green, 1997: p458.

The relationship between anxiety and uncertainty among patients has been suggested (e.g. Fallowfield, 1991; Ogden et al., 2002). Indeed, Baile et al. (2000) note from their survey of oncologists that, "being honest but not taking away hope" was reported to be one of the most difficult tasks when communicating with patients. Second, presenting information about continued threat and uncertainty in the context of treatment meetings, where the action recommended is hoped to be ameliorative or at best curative, is a potentially difficult task to 'pull off' comfortably[8]. Notwithstanding, information sharing of this kind *is* achieved. Let us view how this is so.

In *Extract 6.4*, following diagnostic embellishment, the doctor introduces the 'indeterminacy' of the patient's situation.

[8] Throughout I refer to doctors but this is not to the exclusion of the possibility that it is often other health professionals who inform patients about bad, good and uncertain news.

Extract 6.4 (Case 3.)

01	Dr:	↑HOPE↓fully he's removed all the cancer there is (.) and	←a.
02		(.) it wouldn't ↑come back but (.) cancer being ↓cancer	
03		one can never be sure=	←b.
04	Pt:	=°no°=	
05	Dr:	=and the par↑ticular type of cancer this ↓was (.) does	←c.
06		have <alittle bit> of a tendency (.) to ↑spread >deep:l<y	
07		into the tissue in directions that we ↑can't (.) readily see	
08		or the pathologist can't see (.) um: and so (.) there ↑might	
09		be some disease left behind and their might not (.) and	
10		there is no way of tell↑ing (.) but IF there ↑is (.) there is a	
11		good chance that it can be controlled=	←d.
12	Pt:	=yes=	
13	Dr:	= by giving you some radiation treat↓ment=	
14	Pt:	=umhum=	
15	Dr:	<but it's> BETTer to do it as a pre↑caution	
16		e[ven th]ough you may not need it=	
17	Pt:	[yes]	

In *Extract 6.4,* following information delivery about the patient's cancer, the doctor proceeds to specify what has happened in an optimistic yet uncertain frame by stating that "hopefully" all of the cancer has been removed ('←a'). Via the contrast marker "but" the doctor pairs this hearably *good* news announcement with *bad* news about the indeterminate nature of cancer, "but (.) cancer being ↓cancer one can never be sure=" ('←b'). The patient receipts this news "°no°", which offers agreement with the doctor's assertion, and the prosodic characteristic of quiet tone is suggestive of a bad news receipt (Freese and Maynard, 1998). Using the turn extension device "and", the doctor elaborates his initial news announcement to further specify why uncertainty is especially pertinent to the patient's case ('←c'). His next turn tells the patient that "one can never be sure" is not the end of his turn; the doctor has more to say. Once elaborated, the doctor ends his multi-unit turn with a 'brighter' news particle ('←d') in the form of a "remedial projection", "there is a good chance that it can be controlled=", to which the patient provides a "yes" response. The doctor finally specifies (again) that it is "radiation" treatment that is the particular course of action that can achieve

"control" and the patient provides a further 'yes' acknowledgement[9]. The sequence closes with the core message remaining that the patient might not need further treatment, but "precautionary" treatment is a good idea.

This sequence has a number of features that are worth considering, but for now I want to note the pairing of *bad* with *good* and the sequential ordering of the news delivery; announcing the bad first, followed by a *brighter* exit. When delivering news about the lack of certainty, these organisational features of *pairing* and the *power of proximateness* are observable throughout the data corpus. In terms of the possible functions of such an approach to information delivery, Maynard's comment helps:

> ... [A] prominent feature of bad news, as compared with good news, is that the former is interactionally covered or shrouded in particular ways.
>
> 2003: p160.

In a similar way, the doctors' approach emphasises the positive in and through making it sequentially salient.

In *Extract 6.5*, following the explication of the evidential basis for chemotherapy and its potential to reduce the risk of recurrence or neutralize the spread that might have already occurred, the doctor similarly introduces the *no guarantee* agenda and the uncertainty therein. Once announced, the second part of his turn softens the less optimistic and uncertain news.

[9] Organizing news in this way may potentially mean that doctors can enhance the chances of recruiting patients to a particular treatment regime. However, lay members might also orient to the medical procedures available. Beach's (2003) work on telephone calls between a family whose mother has cancer provides the following example:

Son: Whadda you do with this kind of thing
Mom: Radiation chemotherapy

[Source: Beach, 2003: p183].

Extract 6.5 (Case 4.)

01	Dr:	=it doesn't (0.5) guaran↑tee the disease isn't going to	←a.
02		come back	
03		(.)	
04	Dr:	it reduces the risk of it coming back (continues to explain	←b.
05		risk with no patient uptake for 10 lines of talk)	

In this fragment, we see how the hearably bad news, "doesn't (0.5) guaran↑tee the disease isn't going to come back" ('←a'), following a very brief gap can be paired with the relatively *good* news ('←b'), "it reduces the risk of it coming back". Similarly, in *Extract 6.6*, the doctor implies uncertainty when describing the possible severity of the cancer diagnosis, "*poten:tially* dangerous" ('←a') (my emphasis) followed by the relatively *good* news that the "MAJority of these are cured" ('←b')[10].

Extract 6.6 (Case 5.)

01	Dr:	=<this one> is poten:tially dangerous but less likely to be very	←a.
02		dangerous °than most (melanomas)° so (.) IT'S YOU KNOW	
03		it's potentially serious but (.) the MAJority of these are cured	←b.

Again, within his turn the doctor announces the news that the cancer is *potentially* dangerous and proceeds to pair this relatively bad news with the less threatening news that the majority are cured. In this way, he manages to 'take the sting' out of the danger posed, by ending his information delivery about risk and uncertainty with a bright-(er) news particle[11].

Extract 6.1 is reproduced below in its original context of patient talk. Originally, we saw the doctor's first turn and in that turn the pairing phenomenon was noted. Here

[10] The patient responds by producing the positive upshot of the doctor's news announcement (not shown). These moments of patient uptake are examined later in *Section 6.4*.

[11] Offering worst and best case scenarios in this way covers a number of bases. By stating a 'bad' likely outcome, or uncertainty of outcome, the doctor is *doing being responsible* in two key ways. First, the potential medico-legal ramifications of not presenting both sides of the coin to patients are avoided. Second, negative ethical implications associated with not alerting a patient to the potential for a negative outcome are also avoided. Both factors are 'covered' by delivering the news in such a way. The doctor *does fairness* and openness while simultaneously 'taking the sting' out of the more downbeat aspect of the news.

we see how the meeting develops, following the doctor's initial introduction of what treatment is likely to achieve.

Extract 6.7 (Case 1.)

01	Dr	...°um:° your voice is unlikely ever to be quite as it was before but	←a.
02		ho↑pefully it will be better than it is now and almost back to	←b.
03		normal=	
04	Pt	=right ( )	
05	Dr	( ) obviously we can't guaran↑tee	←c.
06		that it will ↑work	
07		(.)	
08	Dr	but there's a good- a <very good> chance	←d.
09		that it ↑will if it doesn't (0.5) we'l::l er: you ↑will have an	
10		operation but the (chan-chances) are hopeful that ( )	

Again, in *Extract 6.7,* the doctor moves from *bad* ('←a') to *good* ('←b'), and following patient uptake "=right ( )", the doctor moves to the *no guarantee* agenda that signals *bad* news for the patient, "obviously we can't guaran↑tee that it will ↑work" ('←c'). Normatively speaking, the doctor's announcement is of huge consequence to the patient, and, in all of the excerpts so far reproduced, this kind of information has massive implications for how patients might process the information and make their decisions about whether they should or can have further treatment. Patients need to rationalise undergoing treatment that has the potential to induce sickness and discomfort that exceeds that experienced prior to the treatment. Treatments have changed in recent years, but the remarks by Sontag (2001) still resonate today:

> The understanding of cancer supports ... avowedly brutal notions of treatment. A common cancer hospital witticism, heard as often from doctors as from patients: "The treatment is worse than the disease"... With the patient's body considered to be under attack ("invasion"), the only treatment is counterattack[12].
>
> Sontag; 2001: p64.

[12] Below we see a real time example of Sontag's *war on cancer* metaphor in action.

Case A.

01	Dr:	so we've got ↑two ways of hitting it (.) rather
02		than one and we are ↑planning to hit it quite
03		[↓hard
04	Pt:	[yeah

To undergo a treatment that *might not work* or *might not be necessary* is (commonsensically) a difficult course of action to follow. This is especially the case with a treatment such as chemotherapy, which is popularly understood (as Sontag's observations suggest) to be hugely debilitating and which kills good cells with bad. In *Extract 6.7*, however, the announcement of the relatively *good* news ('←d'), that the patient has a *chance* of cure, seems to soften the blow of uncertainty. Notice how the doctor's self repair works to upgrade his announcement from "a good" to "a very good" chance that treatment will work. If, for one moment, we again consider the magnitude of the information being shared, there is potential in the doctor's approach to information delivery to accomplish an interactional comfort and perhaps (speculatively) *hope* - or at least a positive texture to the news being delivered in the here and now.

The's (2002) longitudinal ethnographic study of the management of patients with non-small cell lung cancer also documents in detail the multifarious ways in which health professionals construct the health profiles of patients in such a way as to emphasize the positive. The corollary of this, she adds, might be to underplay the negative. She observed that patients collaborate with the positive 'spin[13]' and in so doing avoid or minimise discussions about that which cannot be achieved. In this way, the longer-term view is truncated in favour of the short term[14]. Contra The's (2002) suggestion, emphasizing the positive in the meetings shown here does not appear to result in a reification of medicine and technology or zero discussion about what cannot be achieved. The *positive* is contextualised in the *uncertainty* of medicine and cancer as a disease[15].

[13] The lexical 'spin' does have negative connotations and it is worth clarifying this a little. Whilst it may seem at points that doctors are sometimes 'spin doctors' in the work they do in these spaces, they are (so it seems) presenting the good, the bad and the uncertain in the ways shown for good practical reasons. That is, they manage to be "honest while not taking away hope" (Baile et al., 2000).

[14] See The's (2002) ethnographic account of lung cancer clinics for a discussion of the public or open discussion of information between doctors and patients vs. a more detailed and candid hidden information sharing about prognosis between health professionals.

[15] I should note that Maynard and Frankel's (2003) discussion of uncertainty and indeterminacy only came to light once this chapter had been written. Whilst it was disappointing to find a direct discussion of the matters discussed in this particular chapter, it was reassuring to find that their single case analysis resonated quite strongly with the analysis of the corpus available for this thesis. It would seem that uncertainty is indeed oriented to by doctors (and patients) while discussing health matters.

In *Extract 6.8,* the doctor directly orients to the uncertainty of the patient's case ('←a'), and mitigates the hearably *bad* import of the uncertainty announcement ('←b') by placing the patient's case in the context of other patients[16]. Next, he closes the sequence by reporting the relatively *good* news that the treatment can reduce the risk of recurrence ('←c').

Extract 6.8 (Case 5.)

01	Dr:	=you're PROBably- you're- you know- BECause	
02		of what Mr X found in the most of the tumour being	
03		completely encased in the lymph glands any↑way	
04		we would hope that (.) he's already done the job that's	
05		required but there's an (↑AIR)- you know- there's a	←a.
06		there's a degree of uncertaint↑y=	
07	Pt:	=yeah=	
08	Dr:	=that's always to be[17] ((third person coughs))	←b.
09		but we can make it a bit less by	←c.
10		giving you some further treatment	
11		(0.5)	
12	Pt:	°right°=	
13	Dr:	=and that's where the radiotherapy comes in	

At lines 4-5 the doctor states, "we would hope that (.) he's (the surgeon) already done the job that's required". Following this optimistic statement via the contrast marker "but" the doctor introduces the *bad* news ('←a'), "but there's an (↑AIR)- you know- there's a there's a degree of uncertaint↑y=". In line with *Extracts 6.1-6.7, bad* and *good* news are paired and presented via a mitigating or normalizing statement, "=that's always to be" ('←b'). The *bad* news of uncertainty, is quickly followed by the relatively *better* news, "but we can make it a bit less by giving you some further treatment=" ('←c'). Following a brief gap the sequence comes to a close with patient acknowledgement[18] of the doctor's treatment proposal "°right°=" (12) and the doctor's sequence closing turn, "=and that's where the

[16] This is a strategy patients might also use while discussing their own illness (see Silverman, 1987).
[17] Often there is something quite idiomatic about how the doctors announce relatively bad news and produce the brighter news exit; "the chances are hopeful", "cancer being cancer" and so forth. Although these invoke a brighter, more positive frame to the news being shared, it is perhaps difficult to formulate a disagreement to such maxim-like statements.
[18] See *Section 6.4* for a consideration of patient uptake and valence ascription.

radiotherapy comes in" (13)[19]. The doctor's turn strikes at the *heart of the matter* and closes the 'sale'[20], and they proceed to plan the treatment.

The doctor's lexical choice also accomplishes a hopeful frame and by positioning the *bad* and *good* information together, the possibilities rather than the uncertainties of radiotherapy remain sequentially salient. Securing patient alignment could (speculatively) be more difficult if the negative, such as the losses over the gains or harm over amelioration, remained interactionally salient. As Maynard (2003) reminds us, "... a particular way of making optimistic projections in the context of bad news is with a statement of hopefulness" (p181). These hopeful or remedial proposals occasion a smooth exit or transition from the relatively bad news announced to a discussion of the details of treatment and later planning of the treatment calendar. Medical meetings, such as these examined in this thesis, are often characterised as invoking and creating a 'can do' discourse, where medical interventions can solve problems that ail the body. Here, we see a 'can do' philosophy *brought to life*, but in a context of *uncertainty*.

Again, in *Extract 6.9,* we see the same organisation of news. We join the consultation at a point when the doctor has explained the patient's diagnosis and treatment options and next proceeds to flag the 'no guarantee' agenda.

[19] Interestingly the minimal response in *Extract 6.8* leads to the doctor stating, "I trust this is what Dr X told you" (not shown), which checks and works to confirm that the news fits with what the patient had already been told. Again, this reminds us that the doctor is one of a team and recourse to other resources is a feature of medical practice in and outside of the consulting room.

[20] This 'sales' analogy works for the treatment disposal moments in *Chapter Four* when doctors provide the evidential basis for diagnosis and treatment. In so doing, they invoke a 'persuasion' format of communicating information (see Silverman, 1987). However, sales personnel will, anecdotally, rarely provide information that signals potential losses or the potential for the 'product' to not work. In contrast, here doctors 'do fairness' by providing information on what treatment might *not* achieve.

Extract 6.9 (Case 6.)

01	Dr:	so ↑having chemotherapy treatment doesn't guaran↑tee	←a.
02		(.) that it won't come back	
03		(.)	
04	Dr:	BUT it has been shown to reduce the ↑risk of it coming	←b.
05		↓back	
06		(.)	
07	Dr:	it has also been ↑shown to improve survival	
08		(0.5)	
09	Dr:	al↓right?	
10	Pt:	°yes that seems clear°	

In *Extract 6.9*, the pairing of bad ('←a) and good ('←b'), and the power of proximateness are observable. Following a (0.5) inter-TCU gap the doctor's "al↓right?" works to solicit a response from the patient. Doctors' use of 'okay' and 'alright' can work to solicit response tokens from patents when responses are not forthcoming. These are two neat ways in which the doctor checks that the patient is 'with him' or 'mind on' and that the patient is aligned to the ID format and the information provided therein.

Extract 6.10, provides an example of how even when a 'no cure' situation is highlighted the organisations of 'pairing' and 'proximateness' are a resource. The relatively *good* news is placed in second position and this facilitates an ordered optimism, whilst the uncertainty of the patient's situation is still topicalized.

Extract 6.10 (Case 7.)

01	Dr:	... ↑if there is indeed spread to the liver then I would <u>again</u>	
02		recommend chemotherapy treatment=	
03	Pt:	=°yes°	
04		(2.0)	
05	Dr:	I'd say (.) a few things about chemotherapy in that situation the	
06		<u>first</u> thing to say is that chemotherapy by itself is not a <u>cure</u>=	←a.
07	Pt:	=nope=	
08	Dr:	=if there is spread to the liver but there is a go↑od chance of	←b.
09		shrinking the disease ↓down with chemotherapy treatment AND	
10		(2.5) <u>also</u> it has been shown to improve both <u>qua</u>↑lity of life AND	
11		<u>improve</u> survival=	
12	Pt:	=yep=	
13	Dr:	=compared to having no chemotherapy treatment	

Bad (←a. = no cure) and good (←b = chance of shrinking disease, improving survival, and quality of life) news are paired and the doctor's multi-unit turn ends with what can be done rather than what cannot be done – that is, being able to shrink the disease down and "<u>also</u>" improve quality of life and survival. On this occasion, the doctor observably invokes a moral adequacy as a doctor and *does* 'fairness' by raising the option of no treatment (13)[21, 22].

Let us consider one final example in *Extract 6.11* when the doctor responds to an earlier query from the patient about cure, "um (.) you know when you've done your (.) radio treatment...would you be able to tell then↑ (1.5) th[at it's cu↑red?". The doctor's answer to this question continues to evoke the uncertainty of the patient's future.

[21] Although it is hard to be categorical due to small numbers, it does seem that this kind of announcement of the possibility of no treatment is often stated most clearly in cases where the possibilities of what treatment *can* achieve are limited in the face of more advanced cancer.

[22] In addition, this extract provides an example of how pending test results, and the consequent diagnostic equivocalness, encourage doctors (and patients) to work with hypotheticals, which adds another layer of uncertainty to these interactions.

Extract 6.11 (Case 5.)

01	Dr:	there's no point at which we can say ↑absolutely but <y'know	←a.
02		once> .hh (.) ONCE you get to about two and a half three years and	
03		you're okay then we'll say well <y'know> the °chances are that ° (.)	
04	Pt:	yeah=	
05	Dr:	=°it's not going to come back°	
06		(.)	
07	Dr:	and at five years <we'll probably discharge you altogether>	←b.

The patient's question is followed by a pragmatic answer in which the doctor talks in to being a long road yet to travel before the patient will exit the 'risky window' of medical surveillance. In short, the *bad* news ('←a') of the uncertainty of being able to announce a cure situation is stated, and following the patient's announcement response (4), the optimistic announcement that the chances of it not coming back are good after two and a half years is followed by, "at five years <we'll probably discharge you altogether>" ('←b'). From this and the previous fragments it is clear that discussing 'risk' and 'uncertainty' invokes the future where the future becomes a concern of the *here-and-now*[23]. Routine, *up-until-now*, conceptualisations of what the future might look like are momentarily and sometimes indefinitely shattered by a cancer diagnosis. In this context, the shape, form, style and content of bad and good news assumes importance. The way in which the doctor's utterance raises a long five-year window of risk whilst still managing to create an upbeat message is skilful – where the "altogether" suggests an extremely positive scenario.

6.3.4 A summary

In the preceding sections, we have seen how the potentially difficult task of informing patients about treatment and the uncertainty therein is managed. It is clear that information delivery is managed in such a way as to enhance the chance of the relatively positive being emphasized, whilst still introducing the 'no guarantee' agenda of both cancer and its treatment. The organisations are doctor led, but as we saw in *Extract 6.11*, information delivery can flow from a patient question. Most

[23] As Giddens states, "The future is continually drawn in to the present by means of the reflexive organisation of knowledge environments... (And) thinking in terms of risk is vital to assessing how far projects are likely to diverge from their anticipated outcomes" (1991: p4).

often, however, patient talk involves the provision of continuers and response tokens to information being delivered and questions are held off until later in the consultation when doctors specifically invite them (Leydon and Green, 2001).

Despite the fact that these interactions are most often played out in the ID format (Peräkylä and Silverman, 1991; Silverman, 1997), patient responses are observably important. Doctors design their turns to encourage some participation. For example, the use of 'okay' to request confirmation of a prior utterance, a silence to monitor for patient responses, 'alright' to pursue a response and finally, not exhaustively, the use of re-completion to cue patients in to the end of a point. On the whole, patients co-orient to the relative good and consequentially background the relatively bad and uncertain news shared. In the following sections I want to show how participants may offer more than a stoic or neutral acknowledgement of information to instead mark news as good or bad.

6.4 Patient uptake: Negotiating the meaning of news

Examination of the data corpus shows that patient responses most often collaborate with the positive frame thus described. Collaboration is hearable through uptake of the (relatively)-good news or through simple continuers, which signal alignment with the preceding talk. Sometimes, (in the corpus considered here) news is marked in quite strong terms, especially when hearably good in nature and we will see how this is so. Though uncommon (in this corpus), two examples of bad news marks, where the bad is at risk of being brought to the foreground, are considered.

Maynard's work on the delivery of good and bad news tells us that the way in which news is receipted is much more than a psychological phenomenon. Rather, the delivery and receipt of news is an interactional phenomenon. Indeed, in the preceding sections we have seen that the way in which deliverers organise their news may have interactional consequences, such as encouraging "stoicism on the part of their recipients" (Maynard, 2003: p121). That is, by pairing relatively bad news with good and ending with the latter, doctors enhance the opportunity for stoic or neutral responses to the information delivered. The possible dangers of 'optimism' include the invalidation of patients' symptoms or concerns in the primary care setting. In these cancer clinics it might be possible that such an optimistic preference may stifle patients' voicing upset, despair or concern about their particular cancer. I have not, however, demonstrated this to be the case.

In terms of how news is receipted, Maynard's (2003) work demonstrates that there can be an asymmetry between the receipt of 'good' and 'bad' information. The former will often be receipted in quite strong terms. For example, "oh great", "that's marvellous"; whist the latter will be receipted in quite neutral terms and we have seen the latter in the previous section. By drawing on examples from everyday encounters and clinical meetings, including HIV testing clinics, cancer clinics and clinics dealing with children with learning difficulties, Maynard shows that in delivering news in a cautious fashion recipients to the news reciprocally organise their responses in an equally cautious manner. This means that recipients interactionally refrain from

marking the character of news when it is negative in character and are more likely to mark news when it is hearably (relatively more) positive.

Maynard's clinical examples are mostly related to diagnostic informing moments. Here, in this corpus, we see that similar patterns traverse consultations that occur in a different country, with a different health care system, and across the care pathway (such as patients who have already been through surgery), in consultations that are set up to deal primarily with adjuvant treatment issues. Let us move to some data to see how news can be receipted in the UK cancer clinic.

6.4.1 Patient uptake: Marking news as good

Earlier in *Extract 6.6,* the uncertain news delivered (lines 1-3) was shown to possess the organizational features of *pairing* bad news with good and the *proximate sequential ordering* of that news. In *Extract 6.12a*, the same episode is reproduced together with patient responses to the information delivered. When these meetings are viewed more fully with the surrounding talk, we can begin to see how the meaning of the news comes to be negotiated in situ. This example also further demonstrates the power of proximateness.

Extract 6.12a. Case 5.

01	Dr:	=<this one> is poten:tially dangerous but less likely to be very	
02		dangerous °than most (melanomas)° so (.) IT'S YOU KNOW it's	
03		potentially serious but (.) the MAJority of these are cured	
04	Pt:	oh good well [that's-	←a.
05	Dr:	[okay <you you're in with a good chance of	←b.
06		being cured even- even though it has> come back	
07	Pt:	yeah	
08	Dr:	you know um	
09		(1.5)	

In *Extract 6.12a*, the patient uptakes the sequentially salient news at the end of the doctor's turn, "MAJority of these are cured" (3) when he states, "oh good well [that's-" (←a). The doctor's contiguous turn in overlap signals upcoming agreement, and does indeed provide confirmation of the good news upshot, "[okay <you you're in with a good chance of

being cured even- even though it has> come back" ('←b'). Together they foreground the positive and background the "potentially dangerous" nature of the cancer.

In *Extract 6.12b* we follow on from *6.12a* and can see that the doctor later demonstrably backtracks from the patient's positive receipts to re-emphasize the uncertainty and the no–guarantee agenda. The fragment is long, but this allows us to trace how the doctor and patient manage a situation of (possible) over-optimism and end up negotiating the meaning of the news shared.

Extract 6.12b (Case 5.)

10	Pt:	right so that's ↑sorted the name out for it. U↑m (.) you know	←a.
11		when you've done your (.) radio treatment	
12	Dr:	um hum	
13	Pt:	would you be able to tell then↑ (1.5) th[at it's cu↑red?	←b.
14	Dr:	[right no well NO IF	←c.
15		YOU THINK ABOUT it I CAN'T TELL THAT YOU'RE	
16		NOT CURED ALREADY.	
17	Pt:	YEAH you're ju[st going for=	←d.
18	Dr:	[you could well be=	
19	Pt:	=EXtra precaution=	
20	Dr:	=so it's just- it's a precaution.	
21	Pt:	yeah	
22	Dr:	<you know> precau- you can't measure the success of a precaution	
23		you can only measure that it's failed	
24	Pt:	yeah	
25		(3.0)	
26	Pt:	but you would- you would expect to know pretty	←e.
27		quickly would you?	
28	Dr:	um, [well	←f.
29	Pt:	[with the- with the speed that they all came at.	←g.
30	Dr:	WELL we will be keeping a close ↓eye on you (.) over the	←h.
31		next months and ye↑ars=	
32	Pt:	=um hum=	
33	Dr:	=and each few months that go b↑y (.) it becomes that much	
34		less likely (.) that it <will come back again.>	
35	Pt:	°oh°	
36		(1.0)	

37	Dr:	there's no point at which we can say ↑absolutely	←i.
38		but <y'know once> .hh (.) ONCE you get to about two and a	
39		half three years and you're okay then we'll say well	
40		<y'know> the °chances are that (.)	
41	Pt:	yeah	
42	Dr:	it's not going to come back °(.) and at five years <we'll	
43		probably discharge you altogether>.	.
44	Pt	oh smashing	←j.
45		(2.0)	
46	Pt:	oh w-well at least you can see the END	
47	Dr:	(ye(h)a(h))	
48	Pt:	the end's in sight y'know you're looking at WELL	
49		[five years.	
50	Dr:	[AFTer-after-AFTer this treat-, AFTER this treatment, um, y'know	
51		the appointments will be fairly frequent over the first year or so...	
		((Continues))	

We already know that *Extract 6.12a* commenced following a patient initiated question, "WHAT sort of cancer was it?" (not shown here). The doctor informed the patient that it was a skin cancer and detailed the various sorts of skin cancer[24]. Eventually, the doctor announces that the, "MAjority of these are cured" (3). As discussed, the patient clearly receipts this as good news and, the doctor's contiguous turn, "you're in with a good chance of being cured", despite the fact that the cancer has returned, signals agreement with the patient's positive evaluation. At the end of *Extract 6.12a*, the patient receipts the news "yeah" and the doctor utters an inter-subjectivity marker "you know um".

Extract 6.12b follows on from the doctors' turn, "you know um" and a (1.5) gap (9). Over four lines, including a doctor-produced continuer, "um hum" the patient produces a second question, "right so that's ↑sorted the name out for it. u↑m (.) you know... when you've done your (.) radio treatment... would you be able to tell then↑ (1.5) th[at it's cu↑red?" ('←a' & '←b').

[24] It is worth noting here that despite the place on the illness path, this patient is still requesting what might be thought of as quite rudimentary information about his cancer i.e. the name of the cancer. Herein lies a significant reminder of the importance and utility of the strategies witnessed in *Chapters Three* and *Four*, where the doctors seek patient perspectives and knowledge before progressing the meetings to describe the cancer diagnoses in more detail.

The question is hearably targeted at seeking some certainty from the doctor about him being able to detect or announce a 'cure situation' at some point in the future. The (1.5) intra-TCU pause expresses some hesitancy; indeed it provides space for the doctor to guess the question. Prior to the completion of the patient's question, the doctor does respond in overlap, with raised volume, which works to seize the floor and his turn initial, "right no well," ('←c') forecasts a dispreferred action (Pomerantz, 1984b). Nevertheless, the doctor's turn-shape skilfully works to uphold an affable-agreeable meeting. For example, rather than stating, "no I can never tell whether you're cured", he states, "NO IF YOU THINK ABOUT it I CAN'T TELL THAT YOU'RE NOT CURED ALREADY" ('←c'). This announcement works to accord the patient with the theoretic capacity (Silverman, 1987) or powers of reason to be able to work out that there will be no way the doctor can tell whether he is cured. The doctor's utterance deflects from the negative of the patient potentially never being cured or never being able to tell, to the inverse and more positive situation of possibly being cured *already*. Thus, the preferred frame is upheld and the interactional discomfort that might arise from a more overt retreat from the patient's search for security is averted.

Next, the patient works with the doctor by offering a candidate rationale for doing the treatment as a "precaution" ('←d.') and over seven lines (17-24) they agree on the precautionary rationale of embarking on a course of radiotherapy treatment. The patient produces an agreement token "yeah" (24) and following a (3.0) gap produces another self-initiated question, "but you would- you would expect to know pretty quickly would you?" ('←e'). The patient's question begins to formulate a candidate answer "you would- you would" and ends with "would you?", which is query intoned. The doctor's response is prefaced "um [well" ('←f') which indicates further resistance to the patient's search for security. The patient anticipates upcoming disagreement and produces an elaboration of his rationale by producing a "my side telling" (Pomerantz, 1980) based on his experience of the cancer coming so quickly in the first instance, "with the- with the speed that they all came at" ('←g')[25]. Again, the doctor prefaces his adjacent turn with "WELL" and continues to specify what they will do, "keeping a close eye..." ('←h'), thus avoiding any direct mention of what they will *not* be able to do. The doctor explains that the risk of recurrence will diminish over time and the patient

[25] The patient's cancer arose following a shaving accident and the tumour developed rapidly on his cheek over a week or two.

provides a newsworthiness change of state token "oh" (35), which marks the information as *news-for-me*.

The doctor informs the patient about the lack of certainty of being able to declare a 'cure situation' ('←i). Via the contrast conjunction "but" he begins to discuss the future point at which optimism around cure will be possible. Again, following the paired news (37-38) and the positive projection at the end of the doctor's TCU, the patient ascribes valence to this news through his very positive formulation, "oh smashing" (←j). In this way, the patient optimistically constructs himself as someone who is likely to survive the five healthy years ahead at which point observation through follow-up will cease. The doctor's response suggests a less optimistic framing of the long wait ahead, indeed the (2.0) gap following the patient's assessment "oh smashing" forecasts possible disagreement. The patient's positive evaluation of the five-year window potentially conflicts with the doctor's cautious management of information that draws on and is situated in a *medical model* focus, which is predisposed to viewing 'bodies that are always ready to fail' (Lane, 1995). Indeed, we can see that the doctor works to downgrade good news receipts by this patient by restating the uncertainty of cancer and the ever-present threat of recurrence.

Following the doctor's silence, the patient articulates what his "oh smashing" receipt might mean i.e. that there is an end in sight (46). Still, the doctor resists colluding with a very positive assessment of the situation through his weak (laugh intoned) agreement turn "(ye(h)a(h))" (47). The patient reiterates the 'end in sight' point whilst explicitly elaborating upon this point to demonstrate he has not lost sight of the (long) five-year window of observation (48-49). Finally, in overlap, the doctor returns to the post treatment follow up and topic shades to discuss the details of treatment, "[AFTer-after-AFTer this treat-, AFTER this treatment, um, y'know the appointments will be fairly frequent over the first year or so (continues)..." (50-51). There the doctor returns to the more immediate plan of treatment and then follow up and recasts the temporal quandary to within "the first year or so". In line with The et al. (2000) the future is "truncated" in favour of the discussion of more immediate matters.

The doctor's resistance to the patient's pursuit of certainty around cure and the potential for rapid detection of cancer if it were to reoccur is clear. Over a series of

turns, the doctor invokes the primacy of the 'devil of uncertainty' (McKenzie, 1998) and the no-guarantee agenda is upheld[26]. The characteristic positive 'spin' is simultaneously accomplished in and through the doctor's *lexical* choice, *pairing* and *sequential ordering* of information. Once the doctor has reformulated the patient's cancer trajectory to be a longer and a less certain one than that suggested by the patient's questions, the patient collaborates with this backtracking from certainty and downgrades his initial positive or hopeful, "oh smashing", to a more pragmatic "at least there is an end in sight".

Maynard suggests that the preferred form for a "remedy", such as what radiotherapy can do to improve a patient's prospects, is for the deliverer to offer it and its dispreferred form is for a recipient to request it (2003: p152). In similar fashion, here we see the deliverer resisting the recipient's search for certainty. It is the deliverer's remit to set the goalposts of optimism. However, there is a danger that the 'goalposts' might be unclear and patients might just 'overdose' on the relative good, the corollary of which may be to overly 'detoxify' or interactionally "shroud" the relative bad. This, in turn, risks a situation in which the recipient to the news exits the consultation with an unrealistically positive message.

Apart from indicating how information is shared in these potentially tricky meetings, we see clear examples of how news is not intrinsically good, bad or uncertain. Rather,

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[26] On a few occasions requests for information on the likelihood of cure are held off until question time, when the doctor invites questions from the patient before closing (Leydon and Green, 2001). Here we see an example of this, where they openly discuss a need to be "positive" (see Wilkinson and Kitzinger, 2000), while avoiding any statistics or certainty on the matter of cure.

Case B.

01	Dr	any ↑questions so ↓far
02	Pt	y↑es (°after °) and as what you ↑said (.) I hope the
03		cancer (.) will be taken away by (.) the [↑radia↓tion]
04	Dr	[( )]=
05	Pt	= (°I can only trust that you will do your best °)
06	Dr	°okay well thank you°
07		(.)
08	Pt	°yes° ([ )]
09	Dr	[we↑'ve GOTTA] be opti↓mi↑stic
10		↑HAVEN'T ↓WE=
11	Pt	=YE[ah oh yes::]
12	Dr	[um <y'know>] ↑um:=
13	Pt	=we've got to
14		(2.0)
		((Next the doctor topic shades to say that radiotherapy is the way to reduce risk))

the meaning of information is negotiated and renegotiated by parties to the talk and on a turn-by-turn basis. This negotiation may be relatively quick or may require extra work and backtracking until the delicate balance of *openness* and *hopefulness* has been safely struck. Balancing the good, bad and uncertain is skilfully accomplished in a variety of ways. Here we have examined some of the organisations that appear to be at the heart of this accomplishment in the clinics studied.

Let us consider a few shorter examples of good news marks. In *Extract 6.13* (originally featured in *Extract 6.7*), the patient produces a positive upshot formulation to the doctor delivered information.

Extract 6.13. (Case 1.)

01	Dr:	...°um:° your voice is unlikely ever to be quite as it was	←a
02		before but ho↑pefully it will be better than it is now and	←b
03		almost back to normal=	
04	Pt:	=right ( )	
05	Dr:	( ) obviously we can't	←c
06		guaran↑tee that it will ↑work	
07		(.)	
08	Dr:	but there's a good- a <very good> chance that it ↑will if	←d
09		it doesn't (0.5) we'l::l er: you ↑will have an operation	
10		but the (chan-chances) are hopeful that ( )	
11	Pt:	but it looks:: (.) in my favour (like)?	←e
12	Dr:	yes: yes the statistics are strongly on your side	

In *Extract 6.13*, bad and good (←a & ←b, ←c & ←d) news is paired and each of the doctor's turns end with the relatively positive projection (←b, ←d). The doctor's bright-(er) side exit, "but the chances are hopeful" (10), is followed by patient uptake in the form of a gist statement which seeks clarity of his 'chances', "but it looks:: (.) in my favour (like)?" ('←e'). As with *Extract 6.12a*, the doctor affiliates with the patient's positive assessment when he states, "yes: yes the statistics are strongly on your side" (12). This nicely demonstrates the power of proximateness, as the doctor's positive framing and the sequential ordering is marked by the patient and together they work to uphold the *locally-accomplished-ordered-optimism*.

It is worth emphasizing again that the optimism is set within and balanced by a general context of uncertainty about treatment possibilities, and not a potentially unrealistic certainty, as is popularly reported in some of the social scientific literature. Here we have clear examples of doctors (sensitively) orienting to uncertainty. Still, within this uncertain context it is the positive that is foregrounded and not the particles of the news that flag the no guarantee agenda or, in particular, the possibility that the cancer will return and result in further treatment in the form of an operation.

In *Extract 6.14* below, the doctor outlines diagnostic news pertaining to the patient's lymph nodes, "all fifteen of those lymph nodes were CLEar there was no cancer in them=" (←a.).

Extract 6.14 (Case 8.)

01	Dr:	=and in your case there were fifteen lymph nodes	
02		re↑moved with the specimen (.) and all fifteen of those	←a.
03		lymph nodes were CLEar there was no cancer in them=	
04	Pt:	=oh (°that's good news then°)	←b.
05	Dr:	which is good yes alright?	←c.
06		(1.0)	
07	Dr:	NOW if I can tr:y and explain (.) how that <sort of>	
08		influences our decision-making, okay?	
09	Pt:	(°yeah, on the tape, yeah go on°)	

Earlier, I noted the importance of the prosody of talk in achieving the positive frame[27]. Here we see that the doctor's intonation emphasizes the "all" and "CLEar" (←a.) and his repetition of the news, "there was no cancer in them", also works to invite the patient to attend to these salient particles. The patient does so but produces the good news upshot in a cautious way through lowered volume and with a flat prosodic character, "=oh (°that's good news then°)" (←b.). This (possibly) displays that it is not the patients' business to be certain about the diagnostic implications of such news. Notwithstanding, the patient's upshot formulation hearably displays a change of state in knowledge and exhibits understanding that the opposite scenario of lymph-node-involvement would, in fact, be *bad.*

[27] I should reinforce a general comment already made about tape quality. The difficulties of recording in a busy clinic environment did mean that the quality varied across the corpus collected. Where possible this has been transcribed.

The doctor's next turn aligns with the patient by drawing on her lexical choice, "which is good yes alright?" (←c.); this works, therefore, to reinforce the patient's understanding or interpretation. Next, the doctor produces an agenda statement, which projects further ID about what that *good* news means in terms of treatment. The doctor's response is in line with Maynard's (2003) observation that, after hearing bad test results, patients may utter exclamations but otherwise, appear to be stoic. By contrast, when they receive good outcomes patients generally utter positive assessments, after which health professionals are likely to agree (p186).

Overall, we see further evidence of Maynard's (2003) suggestion that good news tends to remain interactionally exposed, unlike its counterpart of bad news. For example, in the corpus examined for this thesis we never see an equivalent action whereby the doctor states, "which is bad yes" (this is not to say it does not happen). Good and bad tidings are treated asymmetrically; good news gets reinforced, while bad news is less likely to be so treated.

Let us view another example. *Extract 6.15* is extracted from the same consultation as *Extract 6.14*. On this occasion the doctor shows us an alternative way of packaging information about treatment when he highlights what he *would* have said *had* the cancer been worse.

Extract 6.15 (Case 8.)

01	Dr:	... <NOW if ANY of THOSE> lymph nodes had been (.) invo↓lved=	
02	Pt:	=yes=	
03	Dr:	=the risk of recurrence would have been much higher (.) and I would	
04		have categorically said you should have ↓chemotherapy ↓treatment	
05		(.) alright=	
06	Pt:	=there would have been no option, yeah?=	
07	Dr:	well th-th-there [would be the, be the OPTion but I would have	
08		strongly recommended]	
09	Pt:	[there would be the OPT- BUT YOU'D	
10		S:TRONGLY RECOMMEND IT] yeph, exactly but we've got	
11		Duke's B	
12	Dr:	but we've got Duke's B	
13	Pt:	°right°	
14	Dr:	now what Duke's B means is that the risk of recurrence is ↓less to	
15		↑put (.) that into a context (.) <if I'd been saying it was a Duke's> (.)	
16		C I'd have been saying the chances of it recurring would have been	
17		between 60 to 70%=	
18	Pt:	=(°Christ°)=	←a.
19	Dr:	alright BUT THAT was a Duke's B and WEll differentiated <well to	
20		moderately differentiated> I would say that is about a 30-40% chance	
21		of it reoccurring which means turning things the other way round	
22		there's a 60 to 70% chance that if we do nothing more	←b.
23		[you've been cured by the operation that you've had alright=	
24	Pt:	[( ) =um=	

The patient's response (←a.) is a comment on the hypothetical risk of recurrence and in this way renders it as a reaction to what may have been. The doctor works to emphasize the positive, "turning things the other way round there's a 60 to 70% chance that if we do nothing more [you've been cured by the operation that you've had, alright" (←b.). Following the patient's continuer, the doctor produces the next topic, "now in terms of chemotherapy treatment" and continues to provide information about the remedial action that can be taken in the form of chemotherapy treatment. Ending with a positive forecast, "there's a 60 to 70% chance that if we do nothing more [you've been cured by the operation that you've had, alright=", helps to facilitate a smooth topic transition and is in line with how news is organised throughout the corpus. If the 30-40% chance of recurrence remained more strongly interactionally salient, movement to new topics would potentially be

problematic. There are other possible 'nexts' but optimistic forecasts and turn endings are generally designed in this way.

Apart from reinforcing the organisations of pairing and the sequential ordering of news, this example again highlights that news can be produced and cast in a (relatively)-favourable light, by describing the patient's diagnostic profile in the context of other potential worse case scenarios. Other ways of 'normalising' news, in the context of other people is noted by The (2002). She reports that doctors sometimes establish a no-guarantee rhetoric by specifying the uncertainty of life and death more generally. For example, in a consultation with a man with non-small cell lung cancer, whose prognostic outlook was poor, the doctor reportedly stated that he himself might die tomorrow. In other words, a doctor can work to soften the ID by highlighting that there are no certainties for anyone.

6.4.2 Patient uptake: Moving beyond stoicism

In the data corpus collected for this study, marking the valence of a news delivery in strong terms – good or bad – is relatively rare. As already established, this pattern follows Maynard's (2003) observations in everyday and clinical settings. News relating to diagnostic embellishment and treatment is generally stoically received. News is marked as news through change of state tokens, but the valence of that news is most often left unspecified.

In this section, I want to consider two contrasting cases in which news is marked as *bad.* In the first fragment, through their lexical choice, a third party (3P) marks the doctor's news announcement. The doctor works to emphasize the good in the wake of the bad news receipt. In the second fragment, the doctor's news announcement is clearly marked by the "primary consequential figure" to the news (the patient) (Maynard, 2003), through the expression of emotion. On this occasion we see how the doctor *recovers* the situation when 'flooding out' threatens (Goffman, 1981). In differing ways both examples demonstrate the collaborative nature of these interactional episodes and the range of responses available to participants during action sequences involving the delivery and receipt of news. It also provides an additional demonstration of the primacy of positivity in these meetings.

In *Extract 6.16,* we join the consultation at a slightly earlier juncture, where the doctor commences the diagnostic embellishment prior to his recommendation for chemotherapy.

Extract 6.16 (Case 9.)

01	Dr:	now if I can (.) go over what was found (.) and then (.) take	←a.
02		things from there (.) for you. al↑right (.) <as you know> there	
03		was a (.) cancer (.) it was a (0.5) <what was called a> (.) a	
04		(ductile carcinoma [a ductile)	
05	Pt:	[a ductile ( )	←b
06	Dr:	yes okay	
07		(1.0)	
08	Dr:	.hhh THe s↑ize of it (.) <I think it was> dif↑ficult to (.) yes okay	←c.
09		(1.0) .hhh THe s↑ize of it (.) <I think it was> dif↑ficult to (.)	
10		measure it exactly (.) but they (.) reckon it was about 70	
11		millimetres=	
12	Pt:	=right=	
13	Dr:	=in total (.) which is about (.) two and half to three inches (.) in	
14		fact two and a half inches.=	
15	Pt:	=r[ight]	←d.
16	3P	[(christ)]=	←e.
17	Dr:	<so that ↑was> (.) BIGGER than a↓verage (.) certainly (.) the	
18		G↑RADE of it (.) was (.) a grade two. or moderately	
19		differentia↑ted (.) which is <certainly> BETter than being ↑a (.)	
20		grade thr[ee] (.) tumour al↑right .hhh	

The doctor opens the news delivery with an agenda statement, "now if I can (.) go over what was found (.) and then (.) take things from there (.) for you. al↑right", and a summative knowledge proposal, "<as you know> there was a (.) cancer (.)" (←a.). Following the patient's repetition of the doctor's formulation of the cancer (←b.), the doctor elaborates his initial announcement and proceeds to describe the cancer in further detail including, most significantly, its size (←c.). The perturbed delivery takes place over several lines, and just includes a patient produced response token ("right").

The doctor first describes the tumour in millimetres (10-11) and then in inches (13-14) and in this way clues the patient in to the key message being delivered; maximizing the opportunity for the patient to understand the measurements provided. The patient

responds "right" (←d.) and this is overlapped by the third party's comment (3P), "Christ" (←e). Leaving the extract for a moment, it is not insignificant that the third party rather than the primary consequential figure to the news produces the negatively valenced "Christ" response. Again, quoting Maynard (2003):

> ...We need to understand that the stoic response is characteristic mainly when the tidings are bad and are presented to a person who is of central consequence in the news. Other kinds of news deliveries do not so regularly involve stoicism on the part of the recipient. To the contrary, upon hearing news that is *mainly about others*, or that is good news about oneself, recipients usually assess the news verbally in relatively unrestrained strong terms.
>
> 2003: p121.

On this occasion, and in line with Maynard's comment, it is the third party who utters the strong response. It is difficult to demonstrate that this is a receipt of bad news with regard to the patient or if it is a comment on the size of the cancer that has been removed (the size of the cancer is large and thus it may equate with a bad news receipt). However, the response is uttered in the presence of the primary recipient of the news. The possibility of strong valence ascription by another in the presence of the party to whom the news relates most intimately does not feature in the literature (as far as I am aware), but here we see that it can and does happen.

The doctor's next turn, "so that was bigger than average ...", skillfully aligns with and renders reasonable the 3rd party's response to the information about the size of the tumour, but he moves to emphasize that the grade and differentiation is better than it could have been. In so doing, the doctor softens the tidings by offering some relatively better news. He pairs relatively *good* news with *bad*, and ends his information delivery about diagnosis with the relative positive, "which is <certainly> BETter than being ↑a (.) grade thr[ee] (.) tumour. al↑right .hhh" (19-20). In short, he frames the news announcement as *not-so-bad-news* and proceeds in this way (not shown) throughout the consultation. For example, he states that although there was vascular invasion (*bad*), at least the cancer was oestro-receptor positive (*relative good*) and thus likely to respond to tamoxifen (remedial / positive projection). The patient continues to provide unmarked continuers, and chemotherapy is eventually discussed.

Let us consider one more example (*Extract 6.17*) of a bad news uptake by a 36-year-old woman who has attended clinic to discuss chemotherapy, following reconstructive surgery. The treatment recommendation has been made and the doctor proceeds to describe the side effects of treatment. The doctor has already explained the impact of chemotherapy on the immune system and the consequent "risk for infection", and this news was paired with the announcement that they will "keep a close watch" on her. Next, the possibility of "nausea" was mentioned, and this was paired with the remedial announcement that they administer "very good" anti-sickness drugs to combat sickness. We join the consultation immediately following these announcements, when the doctor informs the patient that she can ring the hospital if she is concerned. The fragment is lengthy but it allows us to trace how the doctor delivers the news on side effects, how the patient responds and, later, how both parties move forward to discuss the treatment calendar (again a third party, the patient's mother, is present, but she does not speak English and refrains from direct verbal contribution to the interaction).

Extract 6.17. Case 10.

01	Dr	=okay and you can ring up at any time if there's problems .hhh I'm
02		afraid it's the sort of chemotherapy that it is likely to affect your
03		hair=
04	Pt:	=yes yes=
05	Dr:	=uhm er I'm afraid your hair is quite likely to come out with the
06		chemo
07	Pt:	=mm mm =
08	Dr:	=we might be able to save it w[ith
09	Pt:	[yes=
10	Dr:	=using an ice pack
11	Pt:	yes=
12	Dr:	=we might not=
13	Pt:	=yes yes=
14	Dr:	=if you do lose your hair
15	Pt:	yeah
16	Dr:	firstly we will arrange before you star[t
17	Pt:	[mm
18	Dr:	to get you a wig organised and we do very very good wigs they are
19		excellent
20	Pt:	yes

21 Dr: so we'll get you feeling beautiful ((patient sniffling))
22 Pt: yes=
23 Dr: =won't be quite as nice as that but it will be quite good and
24 people's hair always comes back always always grows back after
25 the chemotherapy
26 Pt: yes yeah
27 Dr: okay
28 Pt: yeah
29 Dr: it's a bit d- hard isn't it
30 Pt: mm mm ((nearly crying – wobbly voice))
31 Dr: the other thing is your periods may become irregular
32 (1.0)
33 Dr: and it's possible your periods might not continue while you are on
34 chemo
35 (3.0)
36 Dr: okay
37 (.)
38 Dr: do you want a tissue
39 Pt: ((crying))
40 Dr: what's er is it the hair or the chemo or is the just everything
41 Pt: ((crying)) just everything (I have to lose everything)
42 Dr: yes it is sad you have to lose so much .hhh yeah it's very hard
43 Pt: ((crying))
44 Dr: and that's why you need a little bit of t[ime
45 Pt: [((crying and speaking in
46 first language with mother))
47 Dr: it will all come back again
48 Pt: it's very hard (
49
50)
51 Dr: yeah it's ( )
52 Pt: ((explains that other people find it hard including mother – tearful
53))
54 Dr: yeah it's hard because you're still her little girl really aren't you
55 yes okay (.) but we'll get on and organise it quite soon and I think it
56 is possible periods could stop that's a possibility
57 Pt: how do you organise ( ) is it like before
58 Dr: yes X will take you outside and help you I think a support group
59 will be particularly helpful for you particularly if we found
60 somewhere that did a bit of massage and makeovers and some nice

61		things you deserve a few treats at the *minute I think X has got just*
62		the thing in mind
63		(.)
64	Dr:	.hhh so we'll try and make things a little bit easier for you
		((Continues))

In *Extract 6.17*, the doctor's announcements are designed in a similar way to all of the pre-closing extracts where the doctors state the uncertainty of what treatment can achieve. That is, *bad* news is paired with *good* and the *good* news, which is often formulated as a remedial projection, is placed in second position. For example, the announcement about hair loss, "I'm afraid it's the sort of chemotherapy that it is likely to affect your hair" (1-3), following recompletion of the announcement, is paired with, "=we might be able to save it w[ith =using an ice pack" (8, 10) and failing that a "very, very good" wig will be available (18)[28].

The patient is demonstrably upset by the information and a sniffling noise is just audible around line 21. Following the doctor's further reassurance that, "people's hair always comes back always always grows back after the chemotherapy" (24-25), the patient is audibly crying. Moving away from the fragment for a moment, it was noted in clinic by one nurse to another that this particular patient required a "not too nice" approach because 'when nice she cries and when not so nice she cries'. This observation and many others like them augment the picture provided by the transcribed / recorded data. They tell us that the negotiated in situ orderliness of events in this or that way is informed by other processes, external to the consultation and in particular ways. Indefinite possibilities for alternative turn constructions exist. That the doctor designs turns in the way shown is relevant. The nurse's comment also evokes Maynard's discussion of the enigma of stoicism in the face of adversity. He says, "...a stoic response may mirror a deliverer's cautious presentation of bad tidings" (2003: p152). Furthermore, Maynard suggests that this stoicism is linked to "proposals of remedy" or more particularly linked to what we call here the *pairing* and *power of proximateness*.

[28] We might ask what the alternative could be; is there one? Well, the doctor could say, "we have a wig maker you can visit, because you will probably lose your hair". Thus, the relatively 'bad' would be in second position and the positive would no longer be the salient part of the information delivered.

> Stoic responses on the part of the recipients *indicate co orientation to the recipient's embeddedness in a course of action that requires relatively immediate amelioration.* In their interactional dealings with the bad news, that is, participants regard the transformed social worlds of the recipient as one that urgently needs betterment.
>
> Maynard, 2003: p152.

Returning to the fragment, the doctor orients to the patient's upset and produces an empathic statement, "it's a bit d- hard isn't it" (29) with which the patient agrees. The doctor continues to inform the patient about a potential loss of periods and the patient continues to cry. The doctor responds by stating, "what's er is it the hair or the chemo or is the just everything" (40). The doctor's question contains an embedded answer, which *does* understanding and makes it easier for the patient to ascertain what is required in her answer. In short, the doctor facilitates the patient by offering a number of options from which to choose. The doctor's lexical choice explicitly sets her line of enquiry up as *doing being interested* in the patient's thoughts, feelings, fears or difficulties. The doctor neither continues to emphasize that *all-will-be-well*, nor does she work to pursue the agenda immediately. Rather, she pursues the 'trouble' and attempts to ascertain the patient's particular concerns.

Maynard's (2003) ethnographic investigations of HIV clinics found that counsellors would pursue an emotional response and would do so for very practical reasons. Without the emotional breakdown, it was believed/reported that the therapeutic process would not "move forward". If unsuccessful in soliciting an emotional response one counsellor reportedly ended his sessions with a "hug":

> Once you get into a hug situation they decompensate a little bit, they start crying, and I can really find out more information about where they're really at. And then the real interviewing begins.
>
> Maynard, 2003: p196.

Unlike the HIV clinic meetings, oncologists do not seem to seek to 'crack the emotional nut'. By contrast, a reactive rather than a proactive policy seems to be evidenced in the work that gets done. In other words, if a patient's stoicism is replaced with upset, the doctor may offer empathy, but will do so while (eventually) (re)-

orienting to what can be done. Moreover, and importantly, if a patient does not convey upset, doctors do not generally endeavour to 'crack the emotional nut' in the same way as HIV counsellors. Clinic staff spoke of striking a balance, whereby patients are free to express upset, but their possible upset is not (generally) actively pursued.

Returning to *Extract 6.17*, the doctor's turns work to solicit the patient's reason for her upset, she notes her regret about having to "lose so much" (41), and following a tearful discussion with her mother (not in English), states that 'her mother is concerned'. The doctor's response, "yeah it's hard because you're still her little girl really aren't you" (54), uses the patient's prior talk and momentarily shifts the focus from the up-until-now omni-relevant collection of doctor and patient to *patient-as-daughter* with *mother-who-is-upset* (Sacks, 1992: Volume I, Part V, Spring 1967: p594). The rest of the consultation, following the announcement about loss of periods, entails organising support for the patient.

Eventually, the talk returns to what can be done and the consultation ends with the breast care nurse discussing ways of making the experience easier for the patient. In other words, treatment related matters are pursued and the agenda is upheld. Maynard (2003) points out that despite the departure of the HIV clinic culture of exposing bad from many other 'sites', the "stripping of bad can be on the same organisational plain". In shrouding bad news deliverers seek to maintain interactional order and, in similar fashion, practitioners in HIV clinics who seek a display of emotional affect "regard such responses as facilitating the further flow of interaction". It is "after the evoked display of affect they can talk about a host of things including the needs of the individual..." (2003: p197). In this example we can see a mid-way ground, emotional upset is not sought but when evident is attended to by the doctor. Once done the agenda is pursued.

There are a number of analytic notes to make about *Extract 6.17*, but for the moment I want only to note that when a news announcement is made, patient responses vary. Some offer routine continuers, whilst others might mark the news as 'bad' or 'good'. When the news is bad in character and marked as such, doctors have a variety of

options available to them[29]. Overall, in this long fragment we see that when the patient's concerns become visible (sniffling at line 21 or possibly a little before) the doctor seeks out the reason for upset and continues to highlight (relatively) good news to counter this concern.

Seeing how these situations play out in real time is instructive on a number of levels. The pairing of 'good' and 'bad' news and the *ordering* of that news is a practical resource and this works to offset the negative or at least balance it with some relatively positive information. It is also important to note here that unlike the other fragments analysed in which the talk proceeds at fairly smooth pace towards the treatment recommendation, explanation and then on to planning the first treatment, this meeting took approximately 30 minutes. Moving off of the agenda takes time and so the bad news marks can and do observably have interactional consequences in these very practical terms. Quite simply, it takes work and hence time[30]. But, this works to balance the emphasis on the relative good news with acknowledgement of patient concern.

Next, let us to consider one more case, which contrasts to the main data corpus. The example that follows, although uncommon, is instructive in highlighting a further way in which a doctor might privilege good news. Although this resonates with Maynard's (2003) contributions on the subject, it develops the idea that good and bad are set within a broader context of uncertainty.

[29] The case above compares favourably with 'textbook' recommendations on 'good communication' (see *Chapters One, Two* and *Seven* for references). In particular, the doctor does not pass over the patient's emotional response, but solicits her reasons for the emotion and attempts to deal with the response therein.

[30] They can also, predictably, result in upset among staff in the clinic, not least the doctor and specialist nurses present in the consultation.

6.5 A contrasting case: Doctor-produced valence ascription

So far in this Chapter, doctors have been shown to provide information about treatment and the uncertainty of cancer and its treatment, where the upshot or meaning of this is (generally) left to the patient to state or to work out. As Maynard (2003) suggests, there might be a certain "asymmetry" to this 'rule' and that is if the news is good, then a doctor might just mark it as such. I have just one example of this in my corpus.

In *Extract 6.18,* the doctor announces the low grade of the patient's cancer (2), and rather than leave the upshot of the news to the primary consequential figure (i.e. the patient), the doctor announces, "<so that was> (.) >↓good<=" (←a.). Following the patient's response "yes", which tells the doctor she has heard him, the doctor continues to state that the blood vessels were clear and again produces the upshot of that telling, "which is g↑ood=" ('←b').

Extract 6.18 (Case 11.)

01	Dr:	...the ma↑jority of cancers are grade three, but (.) if it's grade one or	
02		two that's a better prognosis and yours was in fact grade one <so	
03		that was> (.) >↓good<=	←a.
04	Pt	=yes=	
05	Dr	=okay (.) there was no- there was some growth around some nerves	
06		but no growth into blood ves↑sels (.) which is g↑ood=	←b.
10	Pt	=um=	
11	Dr	=BUT <as you've said> there were twenty three lymph nodes	
12		removed and six of those had cancer cells in them=	←c.
13	Pt	=yes=	
14	Dr	=which means there is an increase risk (.) of (.) this reoccurring	←d.
15		<because of ↓that> and really anybody of your age (.) with l↑ymph	
16		nodes ↓involved, we would recommend that you have chemotherapy	
17		↓treatment because ↑chemotherapy treatment reduces the risk of	
18		recurrence of the cancer (.) and has been shown to improve survival,	
19		°alright°.	

At line 1 the doctor begins to inform the patient about the grade of the cancer. He does this by first noting that the majority of cancers are "three", and that grades two and one are better than this (1-2). Within the same turn he moves to say that the patients' cancer was, in fact, grade one. Thus, he implicitly informs the patient that unlike the "majority" she is lucky to not have a grade three cancer. At line 5 the doctor begins to say that "there was no-" but he changes course when he cuts off his turn to instead say there was some growth. This 'bad' news is followed by "no growth into blood vessels" (6). Here we have a demonstration of telling the 'bad' before the 'good' via a self-repair within a turn. This again signals a strong preference / organisation for softening relatively bad news announcements with news that is hearably relatively good (in second position). Eventually, following the announcement about lymph node involvement the relatively good news about chemotherapy being able to reduce the risk of recurrence and improve survival is announced (17-19).

I want only to note that doctors do not generally produce the upshot of the news in this way, and this is especially strong when the news is of a relatively negative character. For example, in *Extract 6.18*, the doctor does not end his turn about the lymph node involvement, "six of those had cancer cells in them=" ('←c') with an upshot particle like, for example, "which is bad". Rather, the relatively negative or bad news implications are left for the patient to work out. The treatment implications of the news are provided and the upshot in terms of valence is left unspoken. As Schegloff (1988) suggested, "while the bearer of bad tidings may... convey the information, she or he may not actually tell it or announce it" (p443). This course of action is just one more way of contributing to the production and maintenance of "a practical everyday (and not just storied) world that has the interactionally produced sense of being a [relatively] benign rather than a malign one" (2003: p162).

6.6 Discussion

> Because bad and good news are such ubiquitous phenomena, it is surprising how little research exists regarding them. ...We are not wanting for journal articles and books about bad news, but most of these, full of advice about how to give such news, are remedial and seldom based on systematically gathered and analyzed evidence. ...[T]here is simply a dearth of attention to good news or the relations between bad news and good news, even though the contrasting forms are intrinsically connected to one another.
>
> Maynard, 2003: p24.

Maynard's (2003) work provides a rich database of examples of how good and bad news can be handled in both everyday talk and in clinical settings. Early analysis led me to his work on news deliveries and his note of the dearth of studies that have considered the relation of one type of news (good) to another (bad), provided a spur to stay with an examination of the management of news, both good and bad.

In this chapter we can see, first and foremost, the existence of an interconnectedness between good and bad in the specific space of UK treatment focussed NHS outpatient oncology consultations. Second, how doctors and patients manage such binary opposition – and vacillate between that which may be construed and marked as bad (you had lymph nodes involved) and good (your cancer was removed) has been shown.

Two key ways in which such information delivery is organized have been identified. First, as Maynard tells us, bad news is "paired" with relatively good information. Second, the relatively good information tends to be placed in second position or at the end of a news delivery sequence, called here the 'power of proximateness'. Both organisations suggest an overall preference system for "optimism". Doctors appear to have a general buoyant inclination, to frame news as positively as possible. This feature resonates with recent ethnographic work conducted in UK cancer clinics with patients undergoing treatment for lung cancer (The, 2002; The et al., 2000).

The power of proximateness or the sequential relevance of the latter component in a multiple component turn helps to secure a positive frame. By putting the (relatively) 'good' news in second position, doctors enhance the chances that it is this (optimistic) information that patients will fix on. Patient recipiency during the meetings suggests that the information in the second / last part of a prior turn is, indeed, likely to become sequentially salient. There are other kinds of evidences available to suggest patients might prefer a *positive* approach to information delivery. For example, Coulter et al. (1998) found that focus groups topicalised the need for risk information to be explained but should be done so, "in a positive and reassuring way" (p33). Another recent article (Kirk et al., 2004) based on interviews with terminal cancer patients in Canada, reported that patients wanted an honest approach to information sharing while still maintaining some level of hopefulness. The second most important area reported was the provision of hope and the need for hopeful messages at all stages of the illness path. For example:

> "I don't mind what I hear, so long as there is a little light at the end of the tunnel you know what I mean?... a little bit of hope there, yes".
>
> [Source: Kirk et al., 2004].

Organising information exchange in these ways also serves a number of practical functions. Positive projections help to enable the particular outcome of topic transition (Maynard, 2003: p183-4). It helps to secure a ripe or "kairos" environment so that doctors can continue to share information about treatment, which is a key task of these treatment meetings. As already noted, Peräkylä (1995) also found in his work on HIV/AIDs counselling that health professionals sought to establish (with their clients) a ripe or "kairos" moment to deliver news which may invoke a delicate or "hostile world". Counsellors do not make announcements or get clients to consider a potentially future "hostile world" 'out of the blue'. This is a characteristic in common with the data considered here and, as Peräkylä suggests, "any focussing of attention on something requires its specific kairos moment, its right time" (p239).

Organising information in the way described makes even more sense if we view the task of communication in oncology through a wider lens to take into consideration broader societal norms, recommendations around best practice and the pressures

associated with the litigious wary times within which practitioners operate. Doctors *have* to present the good, the bad and the uncertain.

Despite the practical pay offs of ensuring the relative good is "exposed" problems can arise from the salient 'good'. In *Extract 6.12b*, it was clear that one particular challenge of information delivery in the context of cancer is managing to emphasize the positive, whilst not overdoing it and in the process losing the 'realistic' character of the news delivered. It risks a situation whereby a patient 'overdoses' on the positive and interactionally shrouds or loses the balance that participants had previously worked to achieve. By contrast, on rare occasions when the positive news is backgrounded or only weakly aligned with, doctors (and third parties) may seek to reinstate a positive frame.

The double binds of practice have been noted in other domains of medicine, such as Silverman's demonstration of a tension between patient choice on the one hand and offering clinical advice on the other (see Silverman, 1987; Chapter 9). More generally, his analysis demonstrates that *any* communication 'technique' has the potential (or even promise) to set up some double bind. One such example is that of medical interviews and the ideal of patient centredness or the 'discourse of the social' and the double binds of the 'whole' person being available to the medical gaze, whether invited or not (see in particular *Chapter 8*); where the 'power' may be more "totalising". In short, the *pairing phenomenon* and *power of proximateness* appear to be effective means of accomplishing an ordered optimism, but also demonstrate the potential to set up some double bind.

It was suggested in the Introduction (*Chapter One*) and Natural History (*Chapter Two*) that a vast majority of the literature pertaining to the oncology consultation suffers from opacity, where normative notions of what constitutes sound communicative practices predominate. This chapter adds to existing work by explicating how doctors might (and do) go about providing "honest" information while still (collaboratively) retaining a "hopeful frame". The scales can so easily be tipped either way, but with patterned regularity participants work to uphold a 'home base' of *(realistic)-optimism in the context of uncertainty*. Orientation to uncertainty leads us to a crucial point.

Although, as Maynard (2003) notes, the participants work to uphold the 'benign' order of events, they do so while invoking a *no-guarantee* rhetoric. Maynard and Frankel's (2003) recent demonstration of an orientation to uncertainty and indeterminacy through a single case analysis suggests that rather than doctors "concealing their lack of knowledge from patients" when dealing with uncertainty, "such a tendency is not apparent" (p407). As here, doctors will discuss "indeterminate results" and will produce "optimistic renderings" while doing so. In this chapter, Maynard and Frankel's (2003) single case analysis is supported and elaborated. The spectre of current and future threat to health is recurrently topicalised in my cancer data, "cancer being cancer we can never be sure" and "there are no guarantees, but we hope the chemotherapy will work".

Further, with such an orientation to uncertainty, rather than there being evidence for a "false optimism" (The et al., 2000) or an unrealistically "benign" order, the uncertainty of cancer and its treatment remains omni relevant in the space of the cancer consultation. Certainty is not invoked on any occasion. That uncertainty utterances appear to be a strong feature in the space of the cancer consultation is worth knowing. For some time, the social scientific literature has criticised the certainty within which those in the medical system frame their claims about medicine (e.g. McKeown, 1979).

Here, in these 'contemporary' examples, we see that statements about uncertainty are made. Doctors (re)-cast the future as replete with uncertainty and yet this particular outcome seems to be managed affably. Patients reportedly fear certainty of death when they are first diagnosed with a cancer. Indeed cancer has for some time been synonymous with death (Sontag, 2001: p8). Perhaps in this light, the talked-about uncertainty of life or what treatment can achieve[31] is a relative good and preferable to 'certain' death for example or a certain no-treatment situation. With this in mind, the uncertainty announcements assume a different and less threatening texture and patient and doctor produced optimism makes sense.

[31] Of course an alternative interpretation of this focus on what may be possible rather than that which is not possible might be a reflection of a continued policy of equivocating about the potential for death by cancer because "dying people are best spared the news that they are dying" (Sontag, 2001).

In contrast to the HIV clinics studied by Maynard, we have seen how the doctors in UK oncology clinics are *unlikely* to encourage patients to flood out. Doctors may alternatively overtly recommend alternative spaces for this, for example, support groups, specialist nurses, individual therapy and beauty therapists. As an aside, this accounts for why, sometimes, the outpatient clinics may hearably be an inhospitable environment for dealing with the psychosocial aspects of patient experiences. We return to such practical issues in *Chapter Eight.*

To return to Maynard, in this chapter we develop his insights into how a relatively less malign (rather than "benign") order is accomplished, within the omni-relevant context of uncertainty. Uncertainty casts a critical shadow over the good/bad dyad but – skilfully – without diminishing the opportunities for 'optimism' or threatening to envelop 'hope'.

PART FOUR - DISCUSSION

PART FOUR is divided into two Chapters. The first, *Chapter Seven,* provides a reminder of what the thesis is about. The chapter primarily focuses on the relationship of some of the findings contained within this thesis to contemporary cancer policy and research. In this chapter I ask 'Why another study of this kind?' is justified in an already saturated research (and policy) domain.

Chapter Eight considers some key contributions of this thesis to conversation analytic work and core themes emanating from the details of the analysis. I consider some more thesis-specific limitations and the possibilities for future work.

7.

Revisiting this thesis, the research and policy contexts

> (...) Here's the purpose. If you're going to have a science of social life, then, like all other sciences of something or other, it should be able to handle the details of something that actually happens. It should be able to do that in an abstract way, while handling actual details.... If you can't deal with the actual details of actual events then you can't have a science of social life.
>
> Sacks, 1992: Volume II; Part 1, Fall 1968; LC 2, p26.

7.1 Organization of this Chapter

In this chapter rather than summarising the findings of data analysis I want to provide relatively briefly a reminder of what this thesis is about (*Section 7.2*). Next, in *Section 7.3*, I revisit the rationale for *another study* by detailing the broader contexts in which the research was situated during its conception; represented here by the cancer policy (*7.3.1*) and research literature (*7.3.2*). Whilst some of these issues were addressed in the Natural History (*Chapter Two*), I want to deal with them in a little more detail to illuminate the rationale for another study of 'doctor-patient' interaction in the medical meeting.

7.2 A reminder of what this thesis is about

> Familiar things happen, and mankind (sic) does not bother about them. It requires a very unusual mind to undertake the analysis of the obvious.
>
> Whitehead, 1925.

This study was designed, conducted and reported as a result of being influenced by the work conducted under the rubric of conversation analysis. A focus on the *mundane* made sense in the context of the work I was already conducting in the cancer domain. It was fortunate for me that others had possessed the "unusual minds" to analyze the "obvious" and had already stamped a path for me to journey along.

I analyzed a range of short and long transcribed data fragments, drawn from a tape-recorded data corpus of outpatient oncology consultations. Analysis aimed to demonstrate some of the recurrent activities and their organization in the production and management of information-about-cancer in the context of (post-operative) treatment-focused consultations. A key aim was systematically to collect and make *visible-reportable* some of the work that goes towards these meetings 'coming off'.

7.3 Revisiting the policy and research: Contextualising this thesis

In the Introduction (*Chapter One*) it was suggested that, with an ever-growing acknowledgement of the importance of providing information for cancer patients, the outpatient consultation provided an interesting and important site for study. I proposed that, together with cardiovascular disease and mental health, cancer is one of the Government's NHS priorities (NHS Plan, 2000). Ongoing (re)-organisation focuses on expansion and reform. Recommendations centre on building capacity to manage and treat cancer more effectively, including diagnosis, referral, access, and, importantly for this thesis, implementing 'patient-centred care' and ensuring 'good communication' (however defined). In line with this policy focus, research has focused on the cancer experience

and communicative practices in and outside of the cancer clinic. Here we revisit some of the policy background and later the communications research context.

7.3.1 The policy context: Beyond rhetoric towards an evidentiary view of action

The goal of providing full information to cancer patients and hence loosening 'information control' in medicine appears to be at the centre of service changes (e.g. 'The Expert Patient', DoH 2001; 'Patient's Charter', DoH, 1995)[1,2]. There has been (and continues to be) specific mention (on many occasions) of the importance of patient-centred care and (good)-communication and information giving (Calman-Hine Report, DoH, 1995). As mentioned, more recently the DoH Cancer Services Collaborative (2004) stated that all health professionals should "possess high quality communication skills" and reiterated the need for communication skills training to be mandatory at all levels (p7). In the current climate it seems that the *discourse of good communication* features in 'all' NHS policy recommendations, to some degree.

Within all of these developments exist two interrelated characterizations of health care practice and the key players. First, implicit in the policy literature (and often the research that provides its foundations) is an assumption that health professionals – doctors, nurses and so on – are not already 'communicating well'. Thus, in place of learning from that which some may already be *doing*, a "social engineering" approach to improving services is patent – where corrective measures are laid out in order to improve that which requires improving[3]. Second, also implicit is an assumption that patients are somehow helpless

[1] Patient Satisfaction surveys, 'citizen juries' and patient 'representation' on a range of committees associated with health care have all serviced the goal of meeting the aim of patient-as-consumer.

[2] This policy and research 'starting point' links to Drew's (2003) comment about an assumption of 'medical control' inherent in much of the work that focuses on doctor-patient interaction or communication.

[3] This is not to deny that some experience poor treatment. Rather, no study should commence with a starting point for analysis that involves assumptions of these kinds or predefined 'social problems'. For example, by starting from a point of patients needing to be 'empowered' the formulation obscures the possibility that patients might also have something to offer; that they might have relevant knowledge and expertise. More generally it privileges the identity categories of 'doctor' and 'patient' / 'empowered' and 'disempowered' with no demonstration of members' orientation to these. Thus, opportunities to view that which participants make relevant are potentially lost.

and hopeless, require *emancipating* from a weak position relative to the controlling powers of medicine / medics and, finally, that patients are, as Michael (1996) critically terms it, "besieged by misunderstanding". Whilst this is a quite extreme characterization and necessarily brief it provides a glance at (and reminder of) the context for this thesis.

Given this backdrop, whilst it is, at least in my view, an exciting time in the NHS with the increasing and widening emphasis on patient rights, the corollary of which is a resistance to individual doctors being the sole arbiters of decision making, the reformist nature of much of the policy and associated literatures is reminiscent of the work of liberal clinicians such as Balint et al. in the 1950s (1957)[4]. Whilst we have undoubtedly 'moved on' in terms of our understandings of what patients may want from a health care system and in the conceptualization of their rights, a great deal of policy and research does not appear to seek to understand the expertise and knowledge of patients, of what they bring to the table so to speak, in terms of 'communication'. Moreover, the 'black box' created by much of the cancer and communications industry often does not aid our understanding of 'how' care is organized, received or delivered. That is, (the rhetoric of) 'good communication' and 'information delivery' remains poorly specified. It is here where a conversation analytic inspired body of work can offer an evidentiary view of 'communication' and thus, it is here where the question of, 'Why another study of this kind?' can (in part) begin to be tackled.

[4] The popularity continues with the Balint Society and the Journal of the Balint Society.

7.3.2 The research context: The political (in)-fighting for improved cancer services

> (...) We live in a cruel world in which, unless we remember what we share, research funders and policy-makers may turn aside from us. The challenge we face is to combine the intellectual rigour of our separate approaches with a willingness to reflect upon and to use what we may have in common.
>
> Silverman, 1999: p410.

Contiguous with the policy drive to improve cancer practice, in the Introduction (*Chapter One*) and Natural History (*Chapter Two*) I briefly proposed that there has been an explosion of interest in the study and evaluation of the management of patient care in the field of cancer. Indeed, I noted that a recent systematic review of the literature concerned with cancer patients' views and experiences confirmed the focus of much of the research: 'The greatest quantity of research... on patient views of cancer services, comes under the heading of Information and Communication and support needs' (Farrell, 2001: p7). As well as a focus on 'patient views', research has attempted to understand communication in the cancer consultation. As already mentioned, much of this has focused on the 'bad news' interview and training doctors in the associated skills to do this 'well'.

A great majority of research in these strands can be classified as methodologically distinct from that offered in this thesis (see *Chapters One* and *Two* for a brief description of this). As I unfortunately came to realize (see Natural History) one central tendency within this domain is that qualitative and quantitative work are still often pitted against each other – needlessly so.

> There is a tradition of opposition between adherents of induction and of deduction. In my view it would be just as sensible for the two ends of a worm to quarrel.
>
> Alfred North Whitehead (Quoted in Rose, 1988).

I take just one example to illustrate this point. Recently, Burkitt-Wright et al. (2004) published a study that sought to understand aspects of the doctor-patient relationship that were important to breast cancer patients. They concluded:

> The further significance of our study is to show that patients are not well served by some forms of communication that are currently thought important, including information, choice, and emotional discussion.
>
> Burkitt-Wright et al., 2004.

This led to the Editor of the *BMJ* suggesting that 'communications training might be misguided' (Smith, 2004). One response (of over twenty, including Leydon and Moynihan, 2004) from an author chiefly known for their work in the particular domain of psycho-oncology and communications training (which we visit in the next section) responded thus:

> Burkitt Wright et al. have not attended one of my group's communication skills courses; yet that doesn't stop them from saying that patients valued forms of communication that are currently not emphasised in training and research (...) Apart from the breathtakingly absurd suggestion that a qualitative analysis of views of 39 women with breast cancer should overturn painstaking research and survey findings gathered by many, their assertions are factually incorrect. I am indignant that our work and that that of others whom I respect receives such short shrift from Burkitt Wright et al. The efficacy of our most recent training courses was demonstrated by improving doctors' skills in all the key areas that the authors seem to believe that only they have ever thought about. Furthermore, more than 3000 patients in clinics throughout the United Kingdom commented in detail about the communication they received in exit interviews and questionnaires. Shame on the *BMJ* for publishing a paper that is likely to help undo all the work many of us have been engaged with (...).
>
> Fallowfield, 2004.

Rather than *difference* being a welcome contribution to a complex problem or refuted on reasoned grounds, this sort of polemic is common (McPherson and Leydon, 2002). This

combative context is in no way unique to the world of cancer research nor is it a recent phenomenon in the social sciences allied to medicine[5]. Strong's (1984) words some twenty years ago still resonate today:

> The various academic disciplines with an interest in medicine often have little in common besides that interest. Outside that area they too are often rival empires and, within it, they still fight over the pickings that medicine has to offer. Medicine may be encircled but the academy has no disciplined army, and is instead a motley collection of fractious and independent tribesmen (sic), who spend as much time fighting each other as they do fighting medicine.
>
> Strong, 1984

As a PhD student it is (relatively) easy to retreat from the (sometimes vitriolic) debates, but it is also easy to surmise the implications in terms of the type of research that preponderantly gets funded. The power of the "social engineering" approach to studying communication (found in much of the communications literature) and the power of the "romantic" notion of capturing cancer patients' experiences endures (Silverman, 1987). Many do, of course, recognize the existence of a conversation analytic body of work (including the ESRC and MRC who funded this thesis), but many are yet to be convinced of its merits in terms of its application (e.g. Gillotti et al., 2002).

In this context, research like that offered by the conversation analytic approach is scant. Hence, in part, 'Why another study' of communication in cancer is justified, especially one that draws on different insights and moves away from the 'social engineering' project[6,7]. Apart from my individual (partisan) view on this, there are good

[5] Of course it is unclear that it could be any other way: "Theories have four stages of acceptance: i) this is worthless nonsense; ii) this is an interesting, but perverse, point of view; iii) this is true, but quite unimportant; iv) I always said so. (J.B.S. Haldane, 1963).

[6] As an aside, during fieldwork, practitioners with whom I came into contact often understood that my work was the same as authors such as Fallowfield and Maguire who are chiefly known for cancer communications research in the UK. When I explained that I was not there to judge how 'good' they were but just had an interest in how clinic life (including the consultation) worked, practitioners still expressed a view that it was about measuring their skills against the gold standards set in the literature. On a separate but related point I had spent two or so hours explaining the study to a consultant oncologist and during the end of our meeting the telephone rang. The consultant picked it up and explained that he could not speak for long because he had a psychologist with him who was doing a "psychological study of communication". No doubt a failing of mine for not describing the research adequately but also some indication of the prevailing understanding of what a study of cancer communication entails.

methodological grounds to propose a need for a greater range of approaches to studying cancer care. In order to demonstrate this I wish to revisit one broad strand of research that is common in the study of cancer and cancer communication (briefly noted in *Chapter Two*). In so doing, I will highlight the limitations of a reliance on such an approach and draw out the insights to be gleaned from this thesis and more generally the utility of conversation analytic informed work in general.

7.3.3 Changing doctors' behaviours: Beyond actors and aggregate codes

> Skills currently targeted by training in communication are diverse and often unclear. They have been influenced particularly by ideas arising from patient centred medicine, psychotherapeutic communication, informed consent, and shared decision-making. Clinicians are therefore encouraged to provide as much information as possible, to offer choice and to discuss emotional issues, and extensive research assesses how well they do. Yet professionals' and patients' views as to what is good communication about cancer can diverge, and patients' satisfaction with a consultation is not always related to observer ratings of the formal quality of clinicians' communication.
>
> Burkitt-Wright et al. (2004)

As I briefly eluded to in *Part One* a core stream of research activity can be loosely classified as quantitative communication studies and these are often tied in with training programmes in communicative behaviours for doctors (and less so nurses[8]). Above, Burkitt-Wright et al. (2004) summarise the influences that inform such work. More generally, policy guidance and governing medical councils have provided a strong basis for such work. Today communication skills' training is big business. In the USA, Australasia and the UK, training in communication skills is now obligatory and has been

[7] This is, obviously, a partisan view, since in conducting this study I have a clear interest in viewing the world in a way suggested by conversation analytic inspired work. Still, this 'interest' does not preclude seeing the great richness and utility of other approaches.

[8] As Mystakidou (2005) points out, "Few nurses have received *adequate* communication skills training" (p177) (my emphasis; I do not quote this to indicate the 'adequacy' or otherwise of training, but to demonstrate that it is generally agreed that nurses have been missed out of the whole enterprise of communication skills training).

introduced as a core component of undergraduate medical training. Research activity is reinforcing of this focus. Insights provided have been particularly influential on the setting of research and policy agendas, and in informing skills training programmes for doctors and other allied health professionals.

As a result of the immense attention paid to research findings on the issues surrounding the importance of information and communication, many methods of giving information to patients and their families have been tried and tested (Dunn et al., 1993; McHugh et al., 1995; Ford et al., 1994; Deutsch, 1992; Tattersall et al, 1994; Mohide et al., 1996; Johnson, 1982; Drury et al., 1996). Particularly evident in the literature are service interventions whereby consultations are recorded and copies provided to patients to allow them to revisit information offered during first consultations (e.g. McHugh et al., 1995). Unfortunately, to date, results have been equivocal, patients do not always report benefits from receiving copies of their consultations, at least not in terms of the measures of satisfaction and information retention chosen by investigators. Notwithstanding, insights gleaned from these studies have influenced a number of UK training programmes aimed at supporting doctors' attainment of core communication 'skills' (however defined). Overall, three broad training techniques are identifiable in the literature (Hearn and Higginson, 1997).

(1) The acquisition of specific skills, and recognition of psychiatric and psychological morbidity (e.g. Maguire et al., 1988a; Razavi et al., 1988; Maguire and Pitceathly, 2002).
(2) Specific skills (e.g. open questions) (e.g. Faulkner and Maguire, 1994; Maguire and Faulkner, 1988a; Fallowfield et al., 2003).
(3) Strategies for dealing with specific situations (e.g. Maguire and Faulkner, 1988b; Fallowfield et al, 2003).

Some of the assumptions that underpin these studies are problematic, as are the recommendations for practice and training programmes that flow from them. I want to point to just two problems:

(1) The use of actors (posing as patients) in training courses for doctors and the residential nature of some of the courses.

(2) Aggregate codification of doctors' communication strategies.

I will take each of these in turn.

(1) After communications training physicians often exhibit 'better' communication skills, as defined by the skills programmes, such as more obvious attempts to ask patients if they have any questions. Shilling et al. (2003) found an increase in, "more desirable behaviours including the use of open and focussed questions" (p609). Attempts to tie these changes in communicative practice to patient outcomes, such as increased satisfaction, have so far been unsuccessful or equivocal (Hulsman et al, 2002; Shilling et al., 2003). In addition, there is no strong evidence to suggest that training sessions improve communication in practice on a long-term basis. Just one study to date (Fallowfield et al., 2003) shows enduring improvements (fewer closed questions, but still empathic work diminishes over time). So-called "ineffective" behaviours such as blocking or asking closed questions tend to be reduced in the short term, immediately after training, but these improvements are not consistently sustained over time (Faulkner and Maguire, 1994) and might not transfer to real practice situations (Heaven, 2001).

> ...Doctors do not transfer these learned skills to clinical practice as comprehensively as they should. Offering doctors feedback on real consultations should ensure more effective transfer of skills.
>
> Maguire and Pitceathly, 2002: p699.

More significantly, there is a critical point here to be made about the reliance on actors for training purposes and the abstraction of doctors' behaviours – as already suggested, the patient appears to be 'missing'. This is "paradoxical" because attempts to train doctors are often framed as attending to the needs of patients and yet, "in censuring medical practice for silencing the voice of the patient, such research has itself largely ignored the role of patients in their interactions with doctors" (Drew, 2001).

Abstracting doctors' actions from the circumstances of their production also has the effect of anchoring the 'problem' of communicating information firmly in the hands of doctors. Consequentially, communication comes to be formulated as a one-way process, where the doctor tells and the patient receives (Pinder, 1990; Costain-Schou and Hewison, 1999). Even in this relatively small study it is clear that, to differing degrees, patients can and will influence the content and flow of the interaction. Patients might provide minimal responses or extended storied accounts when asked a question during history taking, they might ask unsolicited questions, resist optimistic framings of relatively bad or good news or (not exhaustively) seek out more optimistic framings than that offered by a doctor. So too they might provide alternative or technically involved summaries of their diagnostic status. In short, and to quote Drew (2001):

> Patients make initiatives and pursue agendas and objectives which arise from their perspectives. They may not always be successful in the 'negotiation process'... but there is no doubt that patients are fully reflexive participants.
>
> 2001: p267.

The apparent 'invisibility' of the patient is, thus, consequential for how well recommendations that flow from 'communications' studies and training programmes apply to 'real time' interaction. Indeed, recently Fallowfield and Jenkins (2004), known for their work in the 'communications training' domain, in a paper considering the management of 'sad, bad and difficult news' noted that there is, "little hard evidence of the effectiveness for transfer of good skills into practice and improvement in patient rated outcomes" (p317). I shall return to some of these points later.

(2) Categorisations of speech acts in some of the more quantitative studies (e.g. Roter et al., 1988; 1992; 1997; Stiles and Putnam, 1989[9]) frequently appear to relate more intimately to analysts' concerns about such things as 'power', 'understanding' or 'sensitivity' on the part of the health professional than to those of the parties-to-the-talk

[9] See Peräkylä (2004) for a comparative discussion of Bales' (1950) approach to interaction analysis, on which more recent approaches are often based, and a Sacksian approach.

(see Peräklyä, 1997b). For example, Hak (1994) in a critique of a paper using similar categorization techniques demonstrates how examples of 'compliance' are used to demonstrate patient oppression, even when there is no evidence of patient 'resistance' in the interactional fragments analyzed. Therefore, categorizations, in part, evolve not from close attention to the talk-in-interaction but to pre-conceived 'operational definitions' of what might be or ought to be *going on*. Indeed, fine-grained analysis in this thesis led us to see that in and through the evidential citation and reference to the foundations for their perspectives on diagnostic details and treatment views, doctors in some senses provide the basis for their expertise to patients. Expertise was not assumed; doctors' "credentials" were actively produced in and through their talk.

Let us take one example of the sort of a communication study that is common in this domain. Ten years ago Butow (1995) and colleagues asserted, "There have been no attempts to obtain accurate descriptions of doctor-patient encounters in the cancer consultation and their relationship to patient outcomes". To fill the gap they turned to CN-LOGIT, which, they propose, "...Offers the opportunity to describe current practice and formally evaluate interventions to improve doctor-patient communication".

Briefly, the CN-LOGIT approach to understanding and describing the communication of information involves counting instances of particular actions (often pre-defined) such as patient question asking. Events are coded in real time (which retains the sequence of events) but normative definitions of 'patient-centred', 'affiliative' and so on are used to categorise participants' actions. Whilst the results are interesting in that the number or percentage of questions asked and responded to are revealed[10], the end product does not detail the actual work that goes in to these activities and the opacity of the communicative project endures[11].

[10] Such counts can be useful in that they allow the analyst to test out the patterned regularity or frequency of target phenomena being collected. They do not, however, provide sufficient insight alone because, for example, process is lost.

[11] More 'manageable' and 'pliable' data are gathered but at a cost (Cuff, 1980).

The literature is burgeoning with recommendations about communication that draw on similar quantifications of doctors' behaviours. For example, Baile et al. (2000) delineated a "six step protocol" for delivering 'bad' news. The steps include 'setting up', which consist of "making a connection" with the patient; 'perception', which follows the maxim "before you tell ask", and it is suggested that this can be achieved by asking open ended questions, to which information can be tailored; and, 'giving knowledge', which should be done in small chunks and patient understanding should be periodically checked along the way. Baile et al. (2000) also suggest that doctors should avoid offering a poor prognosis by stating, "there is nothing more we can do for you". They should instead emphasise what can still be done. In short, the 'six step list or protocol' sounds sensible and provides a useful and accessible summary for practitioners.

More significantly, the 'steps' resonate strongly with some of the practices identified in the data analysed for this thesis. These two approaches – Baile et al's (2000) and that presented in this thesis could be hugely complementary. A summary such as that by Baile and colleagues is useful and easily digested, but the practices described need also to be visible if the list is to be of use to practitioners, for example. The step of, "before you tell ask" provides for an interesting illustration. Whilst this might well involve "asking open questions" it might also involve asking one of many different types of questions (some of which were outlined in *Chapter Three* and *Four*). Further, the interlocutor would, in part, shape the deployment of these. Let us also take the other example of, "emphasize what can still be done". In *Chapter Six* the complex set of practices that might jointly be engaged to accomplish a 'step' that entails emphasizing, "what can still be done" in the context of what may not be possible was explicated in quite some detail.

The massive prima facie similarities between Baile et al.'s (2000) list and some of the practices described in the preceding chapters perhaps suggests that (sometimes) practice may indeed 'live up to' the recommendations contained within the vast literature, or even go beyond that recommended (Silverman, 1997). In part, the data chapters may be seen as demonstrating how some of the directives contained in recent policy and research on

'good communication skills in cancer' can be realised (and viewed) in and through doctors *and* patients lived practice in the space of the consultation (and, implicitly, beyond). The advantage with a CA approach is the ability to see how doctors and patients work together and view the consequences of different practices. Drew et al. (2001) note:

> In contrast to the somewhat static picture provided by techniques involving coding behaviour and then producing statistical aggregations of the relative frequency of coded events, CA [conversation analysis] aims to identify and describe the specific interactional consequences which follow from given verbal practices.
>
> Drew et al.: 2001: p60.

The problem with lists like that produced by Baile and colleagues is also nicely summarised in a comment made by Pendleton (1983) over twenty years ago (cited in Peräklyä, 1997b). At that time he criticized much of the doctor-patient research for a lack of attention to 'process'. He contended that studies had produced lists in similar fashion to a chef listing ingredients for baking a cake, but without the recipe / analysis or method to show how to put the ingredients together to make the cake. Over twenty years later this still (frequently) is the case. In short, "technical access" is a particular strength of the conversation analytic informed enterprise. It permits the opportunity to understand what might lie beneath 'steps' proposed by authors like Baile et al. (2000).

As well as the problem of opacity, categorising the speech acts of one participant, without due consideration of co-participants, can again conceal the ways in which doctors manage potential difficulties in the presence of their co-participants. This is a core point. Rather than train doctors (and patients through the 'Expert Patient Programme') by informing them of "ideal types' of communication or through 'engaging them in role play", "show them how others do what they do and demonstrate their already existent interactional competencies" (Rapley, 2001: p285). Indeed, the use of vignettes and role-play can only ever approximate real time interaction (with patients) and 'how to' texts can end up over-

complicating the skills required; when the skills are lost in translation (Rapley, 2001)[12]. It is, thus, unsurprising that lessons learned are, for the time being, generally rarely carried through over time.

7.4 *Towards a collaborative approach to understanding*

> Complementary development of alternative methods will allow the identification and description of aspects of clinical communication not already recognised or studied. Qualitative methods need to be encouraged, to complement the now standard interaction analysis measures.
>
> Simpson and Buckman, 1991: p1387.

Despite the various problems associated with a 'social engineering' approach to communication (Silverman, 1987), of building ideal types of communication and the gap between these and actual behaviour, which are sometimes acknowledged by those who work in this way (e.g. Simpson and Buckman, 1991: Charles et al., 2000), much of the work has been useful. Valuable pointers on how certain 'doctor behaviours' might influence patient satisfaction, adaptation to a diagnosis of cancer and management thereafter have been provided (e.g. Fallowfield et al., 1995; Fallowfield, 1991; Faulkner and Maguire, 1994; Ford et al., 1994; Ford et al., 1996; Ley, 1988; Maguire and Faulkner, 1988a,b)[13].

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[12] Just as an aside. Recently I was instructing someone on 'how to' conduct their first qualitative interviews. I told the colleague to draw on her everyday skills and tacit knowledge - listen, do not rush, take turns to talk and seem attentive/interested and so on. She was quite disappointed at my basic advice and when pushed I told her to consult a couple of books which deal with interview *skills* and I explained some of the core underlying theories behind different kinds of interviewing. The notion that she ought to "draw selectively from a generic set of interactional resources ordinarily available [to her] as [a] 'competent' speaker" (Rapley, 2001: p291) seemed inadequate. Presumably, the comfortable 'gap' between scientific knowledge and mundane reasoning had been threatened (see Heritage, 1984). Moreover, simply listing ways of doing business falls short of actually seeing how this or that might be accomplished.

[13] Moreover, training occurs in a range of locations (formal and informal) and these can be open to interrogation, as well as the consultation. Pomerantz (2003) discusses different methods of learning and teaching. She reports that interns found watching helpful and lessons can be learnt from non-pedagogic styles. Indeed, non-pedagogic styles were often appreciated by interns because the subtle teaching method saved 'face' because this avoided them being instructed too openly in front of patients

A more collaborative and mixed method approach (while throwing up a whole host of methodological quandaries, especially if analytic similarities do not exist!) might pay dividends. Conversation analytic work is a rare find in these cancer clinic settings. 'Rival empires' *we* need not have and fighting over the 'pickings that medicine has to offer' is unnecessary since what a conversation analyst might say about a particular consultation will, almost certainly, be different (possibly complementary) to comments made by someone nested in the principal research tradition outlined above. The challenge is to (cautiously) seek to harness what 'we' as researchers glean from conversation analytic studies *and* the psycho-oncology literature, the communications body of work and the many interview studies conducted to understand patient views of communication (Drew et al., 2001). We have already seen potential ways of doing this throughout the thesis e.g. interviewing patients to ascertain what has been remembered from consultations, to accrue accounts of 'what should happen' in consultations and tracking what is or is not attended to in stories told by patients in and outside of the consultation.

For now, however, it is still largely the case that while the importance of information exchange is discussed widely, "little research [in cancer] has looked at [or demonstrated] how this is done" (Gillotti et al, 2002).

8.

Revisiting this thesis: Some themes, limitations and future possibilities

8.1 Organization of this chapter

In *this final chapter* I discuss how some of the insights gained from this study contribute to the conversation analytic literature (*Section 8.2*). In *Section 8.3* I consider how the broader themes that emanate from the analysis help to challenge common conceptualizations in the policy and communications literature. In *Section 8.4* I turn to the limitations of the thesis to briefly consider some that were not raised in the first two chapters. *Section 8.5* considers further research possibilities in light of the observations presented and, finally, in *Section 8.6*, I offer a final word and close the thesis.

8.2 Contribution to applied conversation analytic work

Many authors have influenced the writing of this thesis, as the bibliography indicates. More centrally, *Douglas Maynard* (Perspective Display Series; Good and Bad News Deliveries), *Tanya Stivers* and *John Heritage* (History Taking and patient contributions), *Wayne Beach* (Optimism) and *Anssi Peräkylä* (Evidential Citation and balancing authority with accountability) have been critical to the analytic observations made. Let me briefly revisit how this thesis has built on their work.

1. This thesis elaborates on Stivers and Heritage (2001) by attending to a larger corpus, and by considering patient and doctor contributions in detail during history taking.

    a. As they proposed from their case study, a patient may 'break the sequential mould' during history taking and weave their own material into their answer in the service of their own agenda and self-presentation (p180). This is not

unique to cancer meetings or medical meetings. However, the fact that cancer patients in my data recurrently weave "atrocity stories" (Baruch, 1981) about their journey to diagnosis (and defend their actions prior to diagnosis) provides further evidence of the importance to patients of presenting themselves in a morally adequate light when engaged in 'consultation talk'.

b. Unlike Stivers and Heritage's (2001) case study, doctors can and will affiliate with patient life-world narratives or minimal expansions. This is most evident in open interrogative sequences where patient narratives are more obviously invited. Where such affiliation or acknowledgement work is lacking, doctors may be held to account. As an aside, I would like to wave a flag of caution in speaking too glibly about 'open' or 'closed' interrogatives. As I mentioned in *Chapter Four* (see p113) such categorizations are the beginning. They must be interrogated for their sense and function and understood in relation to the turn-by-turn unfolding of talk between parties-to-the-talk. It is not the case that if a question is 'open' it unfailingly 'determines' or sets in motion a particular series of actions.

c. This thesis moved towards producing a clear view on how history taking as an activity might develop over the course of the trajectory and the range of question and answer types produced ('open' and 'closed' interrogatives in *Chapter Three*, foreshortened perspective displays, full perspective display series and summative knowledge proposals in *Chapter Four*).

d. I also demonstrated, across the corpus, the range of responses garnered depending on the solicitation device deployed. Clear differences in patient responses were visible with patterned regularity.

2. Unlike this thesis, Peräkylä (1998) focused on the coordination of the design and placement of the diagnosis in relation to the examination of the patient and the telling of the upshot of that examination.

   a. Peräkylä's examination of primary care meetings shows that the "home base" communicative frame is one of "plain-assertion". In the outpatient oncology

consultations analyzed, diagnostic evidence is explicated in some detail, in more elaborate fashion than that generally found in general practice. "Plain assertions" do not exist (in my corpus).

b. In more pronounced terms, yet in similar vein to the doctors examined by Peräkylä, we see oncologists balancing their (claims to) authority with their accountability for their actions by citing the detailed evidential bases for their claims.

c. I add to Peräkylä's observations by showing potential differences according to primary or secondary care meetings and by focusing on the 'voices' used during "diagnostic citation".

3. Unlike Maynard and Clayman, in this thesis I indicate that the use of 'voices' might serve a different kind of function to that of invoking perspectival "neutrality" or 'eviscerating responsibility'.

   a. (Following Peräkylä) doctors work to demonstrate that their claims and words are soundly based and collegial and the use of different voices is central to this demonstration.

   b. The use of 'voices' worked to show what doctors do not know or have not done first hand, thus reflecting activities of a broader medical team. In so doing, they made accessible the processes engaged to reach a diagnosis and treatment disposal. Doctors are part of a 'we' and as such they animate news / information / activities authored or undertaken by others, at other moments on the care pathway.

4. Maynard and Frankel (2003) have demonstrated an orientation to uncertainty and indeterminacy through a single case analysis.

   a. This thesis dealt with the relationship of the good, the bad and the uncertain across more cases and detailed how a positive frame is accomplished.

   b. The consequence of emphasizing the positive is not a reification of medicine

and technology. The *positive* is recurrently contextualised in the uncertainty of medicine and cancer as a disease. This involves doctors orienting to that which they do not, and possibly can never *know*.

c. Although the work on good and bad news informings resonates with Maynard's (2003) contributions on the subject, it develops the idea that good and bad are set within a broader context of uncertainty.

d. I have built on Maynard's insights to suggest that a relatively less malign (rather than "benign") order is accomplished, within the omni-relevant context of uncertainty.

e. Overall, similarities exist with Maynard's findings and we have seen that patterns traverse consultations that occur in a different country, with a different health care system, and across the care pathway (such as patients who have already been through surgery), in consultations that deal primarily with adjuvant treatment issues.

5. Beach's (2003) work on optimism was also elaborated in a comparative way.

   a. I highlighted that doctors and patients might accomplish optimistic renderings of news shared in a similar way to lay members.

6. In contrast to the HIV clinics studied by Maynard, the doctors in UK oncology clinics are *unlikely* to *encourage* patients to "flood out".

   a. Doctors may alternatively overtly recommend other spaces for this, such as support groups, specialist nurses, individual therapy and beauty therapists.

   b. They do not seek to "crack the emotional nut". An orientation to positivity seems to minimize discussion of emotional matters.

   c. It might be, therefore, that the goal of organizing adjuvant treatment is accomplished without 'emotion'. HIV clinics operate in a different (theoretically grounded) fashion, where emotional reactions are *required* for the counselors to proceed with the job at hand.

More generally, this thesis offers another contribution to a growing body of applied conversation analytic work. Doctors and patients work together to accomplish the broader task of the consultation and organizing additional cancer treatment. Of critical importance are the additional insights into the pivotal place of "expert laity" in-interaction.

In the next section I move to discuss some of the broader themes to emanate from the detailed analysis. I suggest that these may challenge common conceptualizations of communication found in (some of) the health services, policy and psycho-social-oncology literatures.

8.3 Beyond common conceptualizations of communication: Some key themes

In this section I propose that several broader themes or lessons can be drawn from the data analyses shown. These can be linked with and challenge common conceptualizations of patients and doctors and the communicative project more generally.

8.3.1 Beyond a normative conceptualization of History Taking

A large part of this thesis focussed on the work that occurs prior to detailed discussions of chemotherapy or radiotherapy treatment. We saw in *Chapters Three* and *Four* that the History Taking 'phase' in the secondary care meetings described may involve much more than establishing a patient's prior medical history. Rather, during these early moments, doctors and patients work to establish what each other knows, what information is 'owned' by patients and what other health care professionals have relayed, prior to the here-and-now of the consultation. In so doing, we saw how doctors and patients accomplish a common ground, prior to discussions about diagnosis and treatment.

I have tried to convey how the strategies present in the extracts contribute towards '*doing*' a gradual build and cautious execution of a first mention of cancer or cancer

implicative talk. Understanding *that* and *how* doctors and patients jointly achieve a ripe or "kairos" (Peräkylä, 1998) environment for cancer talk to occur is important. Understanding *how* knowledge checks, perspective displays and proposals contribute to ensuring this ripeness or "kairos moment" is also significant; cancer talk moments are "anticipated and prepared for", they do not just happen (Peräkylä, 1995, p275).

Doctors seek to establish a common ground and consequentially seek patient alignment to the agenda of treatment, just as HIV counsellors seek to align clients to the upcoming 'disclosure' of a test result'. These cautious strategies can be used in moments when news or topics are good[14] (e.g. negative HIV result, Silverman, 1997) neutral or bad (e.g. in Maynard's meetings in paediatric clinics where bad tidings regarding developmental difficulties feature, 1991) and, significantly, when the business is not strictly diagnostic in nature, but potentially tricky.

Doctors review the "tellability" in relation to the local environment (ten Have, 2001) and with thought for what Dr X has *said* or *done* on the patient trajectory at other points and what clues and displays have occurred at other points in the consultation. However, it cannot be emphasised enough that the only way the doctor can properly review this 'tellability' (and proceed accordingly) is to get the patient to speak. The common polarity of expert doctors vs. inexpert patients, "besieged by misunderstanding", seems to bear little relation to the patient talk in this thesis.

Whether these steps towards getting a patient to make the first mention of cancer or to do some cancer implicative talk represents 'good practice' or 'patient centred practice' is a moot point. What is clear however is that during these first meetings a) doctors try not to jump into cancer talk both feet first, they test the water and b) doctors will, at points, invite patients to display their understanding or – later in history taking – their alignment with the cancer talk to show that they are 'mind on' (Wooffit, 1992).

[14] Silverman's (1997) study of HIV post – test counselling sessions show that caution is not always a 'good' practice e.g. in the case of good news it can lead to problems.

Although the meetings included for this analysis are not (distally) concerned with diagnosis in the way in which diagnostic meetings are usually framed. Diagnoses are relayed, revisited and rearticulated in order to facilitate a move from *that* diagnosis (however defined and agreed) towards rectification or stabilisation via radiotherapy or chemotherapy. Reaching a point where treatment can be discussed, sensitively and affably, involves a cautious and collaborative[15] accomplishment of mutual understanding of what *has* been happening before discussing what *may* happen next. 'History Taking' is pivotal to this broader project.

Finally, 'bracketing' normative assumptions about the asymmetry of the task of history taking and not focussing single instances of phenomenon, such as 'missing assessments' when, for example, the truncated perspective displays occurred, we were able deepen our understanding of what History Taking involves and how[16]. We also moved beyond the *gloss* of doctors asking questions and patients responding. In addition, we were able to observe how two interlocutors 'get acquainted' throughout the entire history taking 'phase' by referring to long strips of sequentially connected interaction.

8.3.2 Beyond 'failure to disclose' towards detailed evidential citation

Later, in *Chapter Five* we saw how doctors provide the evidential basis for diagnosis and how this action is intimately tied to the action of proposing further treatment (Heath, 1992). While they produced evidence we saw that doctors' shifted their 'production formats' and this functioned to orient to a broader 'medical team', responsible for organising and planning patient care. In and through the evidential citation patients were accorded the "theoretic capacity" to listen to, respond to and understand the information cited (Silverman, 1987). So too, and in line with the work of Peräkylä (1998), we saw

[15] That the work done in these meetings is 'collaborative' or 'affable' is meaningful in terms of future oriented tasks of the participants in these interactions. As Svennevig (1999) says of his studies of 'getting acquainted', "my informants are committed to extensive future interaction and thus have a greater motivation for getting acquainted" (p6). Similarly, doctor and patient will be (most likely) in contact for some months to come.

[16] This is not to suggest that those who employ alternative methods, such as Roter's interaction approach miss detail. Rather, this detail is eventually jettisoned to formulate aggregate codes. Whilst these might be easier to digest for a reader, for example, it does mean that the reader does not get to 'see' how things work.

that in producing the evidential basis for the diagnostic and treatment information provided, doctors avoided a sole reliance on their authority as medical experts. As Peräkylä (1998) hypothesised, the level of detail cited by doctors was greater than that (generally) seen in the primary medical care setting. This difference seemed commensurate with the complexity, uncertainty and demands of specialist medicine, when compared with primary medical care. This invokes an entirely different theory of doctor-patient interaction, where doctors are accountable. In and through inviting patients to tell them what other doctors have said at other temporal moments, doctors openly invite other players – their actions, knowledge, and perspectives - into the communicative game.

In addition, the detailed evidential citation challenges common conceptions of 'non-disclosure' to patients about the details of their cancer (see below, *Section 8.3.3*), whether good, bad or uncertain.

8.3.3 Beyond 'biomedical claims of certainty' towards uncertainty

In *Chapter Six*, the complex interplay between relatively good, bad and uncertain elements of diagnostic and treatment related information, and its delivery and receipt, was explored. Again, of particular interest was the observation that doctors did not invoke an unrealistically certain view of medicine and in particular the treatment of cancer, but instead the uncertainties of cancer and its treatment were raised with patterned regularity. Importantly, even with discussions of uncertainty a positive frame was mutually worked out throughout the consultations. The 'negatives' were softened, but not buried or hidden by relatively 'better' news. Together doctors and patients constantly negotiated "a possible world, an alternative reality, by linguistic means" (Peräkylä, 1995: p239).

Much research has focussed on lack of disclosure to patients who are ill with cancer (e.g. Centeno-Cortés and Núñez-Olarte, 1994; Clafin and Barbarin, 1991; Pistrang and Barker, 1992; Tanida, 1994; Taylor, 1988). As mentioned, The et al's (2000) recent qualitative

observational (ethnographic) study focussed on a lung diseases ward and outpatient clinic in university hospital in the Netherlands. "False optimism about recovery" was found, usually during a (first) course of chemotherapy (equivalent to the meetings analysed at H1). They suggest that "false optimism about recovery" was the result of an association between doctors' activism and patients' adherence to the treatment calendar and to the "recovery plot". They argue that this is a result of doctors not wanting to pronounce a "death sentence" and the patient not wanting to hear it.

This finding resonates in some ways with the positive inclination / approach / preference in the data examined here. It is difficult, however, to view the data as indicating a "false optimism" since optimistic formulations were generally set up in a context of uncertainty, of what treatment might or, significantly, might *not* achieve. However, it may be that the power of placing the optimistic formulation in second position is such that not only does the positive remain *interactionally* salient (generally), but also it is this news that is retained on exiting the consultation space. It is here where a combination of methods might lead to greater insights (e.g. interviews with patients prior to and following their consultations).

We also saw how, by comparing Beach's (2003) investigation of lay talk about a family member's cancer, the action preference of optimistically framing a cancer diagnosis and cancer experience is not just a 'product' of the institutional mantle of 'consultations'. Such optimism can and sometimes will be invoked and managed in other spaces[17].

'Uncertainty' has stimulated interest in the domain of doctor-patient communication (and beyond) for some time. Increasing potential of new technologies and genetic profiling to even predict individual 'at risk' status has also led to growing interest in this domain. The Editor of the British Medical Journal, posed the following question recently (quoted in *Chapter Six*):

[17] In a special issue of the journal Text on lay diagnosis/expert laity in which Beach (2001) reports on his telephone conversations between family members, Drew (2001) states: "it adds another important dimension to the holistic picture which is beginning to emerge of the connections between patients' experiences in their ordinary lives, and their accounts and explanations, and 'lay diagnoses' in clinical

> And—a question that interests me—how do you share the uncertainty that is ubiquitous in medicine and still seem to have expertise?
>
> Smith, 2004.

In this thesis, we have seen precisely *how* doctors might endeavour to share uncertainty while, in similar vein to Peräkylä (1998), still calling forth their expertise in and through their evidential citations. These insights have massive practical relevance. As Maynard and Frankel (2003) suggest, medical training would do well to broaden its scope to include, "the sometimes overarching problems of uncertainty and indeterminacy" (p408). Here, in this thesis, we have real-time examples that could contribute to such an enterprise.

8.3.4 Beyond the bad news interview towards understanding of the full 'social milieu of cancer quandaries'

On a broader note, the data chapters in this thesis have departed from a focus on the 'bad news' interview to focus instead on another element in a complex 'trajectory of care' (Allen et al., 2004). Indeed, by focusing on meetings with patients who already (are presumed to know) their diagnosis we have seen how *other* consultations along the trajectory occasion 'bad news' together with relatively good and uncertain news. This move away from the up-until-now preferred research focus in cancer research on the so-called 'bad news' interview proved useful.

By focusing on other elements at later temporal phases on the patient journey it has been possible to see how doctors and patients offer and receive information when other health care professionals have already been involved and the illness trajectory already commenced. We saw how other players, not present in the consultation, are referenced and brought into the consultation in the here and now.

> As the complexity increases the likelihood of players having access to all relevant information is compromised[18]. Allen et al., p1021.

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settings' (p265-266).

[18] Indeed, it is doubtful that anyone ever has access to all of the 'facts':

By capturing consultation talk some way down the post-diagnostic trajectory we have been afforded a glimpse at the complexity of *the* cancer consultation(s). Diagnoses are not initially given but are embellished, elaborated and confirmed / disconfirmed in quite spectacular detail (by doctors and patients). The illness / cancer is built up based on information gleaned from other moments and other players. Rather than the 'compromise' of participants 'not having all information' posing a problem (interactionally speaking) both doctors and patients work together to share what information each other holds.

Doctors attend to the fragmented journey in their use of the strategies outlined, especially their reference to other structural resources that are external to the here and now of the consultation. It is one way of managing patients who have stopped off at several other 'service points' prior to reaching the meeting, in which they require patients to confirm / disconfirm knowledge or to reiterate knowledge. Knowledge in this sense is incremental and two-way for both patients and health care professionals. This is observable in patient informings to doctors and doctor produced embellishments, in their efforts to introduce cancer and cancer treatment to the agenda.

In summary, research on diagnostic informing is often framed in a static manner and the site of that informing is (often) conceptualised as the 'bad news interview'. The consultations examined in this thesis underscore the incremental nature of information sharing across time and across the consultation trajectory.

"No doctor claims to encompass all of medical knowledge. Each doctor has merely a small part of the wider whole, but each has access to all the rest through the profession..." (Strong, 1980: p30). This thesis has just shown us how doctors make it known to patients that they do not personally hold all of the information about their case, but that they have access to those who do and can work with that information to formulate decisions about treatment.

8.3.5 Beyond one-sidedness: Repositioning patients

> The professional-patient relationship, once characterized as a meeting between knowledgeable expert and ignorant layperson, is now more appropriately... described as a 'meeting between experts'.
>
> Nettleton, 1995: p132.

As we saw in *Chapter Seven* (*Section 7.3*), despite the increasing focus on patient rights and 'expert laity', often the research and policy literature tends to (empirically) background patient expertise, whereby the speech acts of doctors form a key focus. When the work that patients do is addressed, often doctor and patient talk are considered separately and evidence for 'doctor dominance' is proffered when, for example, doctors have higher rates of speech units, which are biomedical in focus. Drew (2003) comments in his discussion of the 'active patient (is not a dope)':

> Much of the research into doctor-patient interactions has focused in various ways on medical control. Whether viewed in terms of management of the agenda (...), questioning, [or] the information which is elicited (during History Taking...)... a principal concern has been to investigate the extent to which doctors putatively maintain control over the interactions.
>
> p31.

In line with the ideas recently espoused in a special issue of the journal 'Text' (2001), it was clear that for this thesis to focus on these such matters and thus on what doctors do (or 'do not do') would prove to be inadequate. Although analysis focused mostly on doctors, we were able to see some of the work that patients do. Far from patients being silenced, they spoke up and sometimes did so in detail. As well as differing from current examples of communication studies, this differs in emphasis and definition of patient roles from earlier sociological 'models', such as Parsons (1951). Frankel contends:

> The trouble with Parsons' formulation, as pointed out by a number of critics...was that it reduced the patients' role to one of passivity and dependency, and the definition of the situation to being totally under the control of the physician. Common sense and experience make clear that patients in a medical encounter bring their own thoughts, feelings, experiences, and sense-making practices to bear on what ever ails them.
>
> Frankel, 2001: p85.

If there is one broad 'headline' message or theme to take from this thesis – though not original - it must be to stress the central role of the patients in the clinic interaction. As Schegloff (1982) points out, talk must not be viewed as 'the product of a single speaker and a single mind (...) even when only one does the talking' (p72). There is still a need for balanced work on doctor patient interaction. Seeing patients as equally important in *interactional* terms will require a move beyond the emancipatory rhetoric and normative characterisations of *doctors'* practice (as good and bad).

> There is a distinct value orientation among many researchers that leads them to celebrate the spoken actions of patients, while being critical of the equivalent work of the professional practitioner. While value-freedom in such matters may be a chimera, an overly ideological commitment to patients (...) should not relieve us of the methodological imperative of symmetry.
>
> Atkinson, 1999: p76-77.

Paradoxically, by attempting (in the end) to avoid a 'value orientation' such as that indicated above and moving away from a focus on 'asymmetry', we have been able to highlight a form of *power* (for want of a better word) in the patients' court, which has macro relevance in terms of patient care. It illuminates how patients act as key 'link workers' in their fragmented cancer journey. They alone hold a full picture of their journey, at least first hand, and have to share that knowledge with professionals over many weeks and months, across numerous organisational settings.

Of course, difficulties may arise when the 'story', relayed by the patient, conflicts with that held by the doctor and his collegially informed knowledge. We saw that one crucial

function of the perspective display series was to minimise these sorts of occasions by first soliciting patient views to enable the adequate tailoring of information to the expressed view. Notwithstanding, it is the case that health professionals rely on patients to report 'on demand' to enable them to proceed with their particular job in a hearably ripe or 'kairos' environment (*Chapters Three* and *Four*). To do their job, doctors *require* patient participation. Peräkylä (1995) has also commented that, "the [HIV] clinic needs the patients' disclosures of their experience as much as the patients need the clinicians to listen to them" (p340)[19].

8.3.6 *Beyond 'social engineering' towards rethinking health care organisation*

As already established, often doctors are criticized for not paying adequate attention to patients' needs (both informational and psychological/supportive). For example, Ford et al. (1996), comment:

> Clearly the ability to communicate effectively is fundamental to the practice of clinical medicine, but it is a skill which many doctors lack.
>
> p1511.

Ford et al. (1996) analyzed audio recordings of 'bad news' consultations in oncology. The main objectives were to conduct a content analysis of information provision and to check the amount of "physician dominance vs. patient dominance". Using Roter's Interaction Analysis System (a modification of Bale's Interaction Process System) they found that consultations were not "patient centred". Rather, the amount of discussion concerning "medical topics from both parties was 2.5 times greater than the amount of

[19] Although patients get to speak up, there are very few discussions in the corpus about 'psychosocial issues'. Patients do not often attempt to introduce such issues but there remains a question of whether this is partly shaped by patient knowledge of what is allowable in these sorts of meetings or whether they simply do not wish to. Either way there is strong evidence that psycho-social morbidity is high among those affected by cancer, where therapeutic value can be gleaned from talking through issues (formally through professional counselling and informally). There might, then, be argument for looking at where this sort of *therapeutic* discussion might best be accomplished.

psychological discussion"(p1511). As already detailed, these sorts of studies and findings are prolific in the cancer communications literature.

However, as already noted, in the 1980s Silverman (1987) indicated that 'social' aspects of patient care might be better dealt with during clinics that are dedicated towards this very different goal. Such a trial clinic was set up for parents with children with congenital heard disease, so that 'family' issues could be raised in an environment that was more likely to have the space to encourage the accomplishment of a ripe environment for such talk. More recently, following their qualitative observational (ethnographic) study, The et al. (2000) found the space of the consultation was not conducive to openness about prognosis. They similarly conclude, "solutions have to be found outside the doctor-patient relationship itself - for example, by involving "treatment brokers"".

These sorts of solutions to providing 'whole patient' care are possibly worth considering in place of social engineering solutions. On a practical level, we saw that to respond to moments of crisis takes time, and although it is clear that doctors should (and as we saw can) respond to patients' emotional needs, there is strong argument for setting up separate spaces for such matters to ensure all patients' are supported, those who exhibit their upset voluntarily in the outpatient clinic, as well as those who do not. As mentioned earlier, at one of my study sites the cancer clinic involved consultations between patients and a specialist information radiographer. During these meetings special attention was paid to patient concerns and questions. These could be raised during the meetings with the consultant, but in recognition of the constraints on the out-patient consultation space, the separate and dedicated meetings were established.

Returning to how patients take the opportunity to answer the 'open' question about 'how their journey started', we can begin to see support for such health service re-organisations. First, a separate consultation, which is openly dedicated to discussing difficulties, questions, concerns and so forth may be able to use patients' 'storied material' more so than (hard pressed) consultants in outpatient clinics in which the

institutional mantle of the consultations occasions a core agenda of organising patient treatment. The richness of patient stories and their elaborations may be easier to respond to at length (where appropriate) in meetings where the agenda is not so focussed on ascertaining a) what has happened before, b) what patients know of that and c) providing the evidential basis for what is recommended or is about to come.

Speculatively, there is something to say for providing a dedicated clinic for patients to allow them to speak to a health practitioner who is less intimately tied to the treatment decisions and management of treatment. Indeed, the increasing popularity of independent information, whether it is from written materials, face to face or telephone information from independent charities, such as CancerBACUP, suggests there is a demand to talk through issues related to the cancer experience with someone other than the key health care provider (Boulton et al., 2001; Boudioni et al, 2001).

Some might choose to argue that this need would not arise if doctors were 'good' at 'communicating' all information to patients. Whether 'good' or 'bad', many of life's quandaries can (often) be helped by discussing them through with an independent party who is not so closely bound to the situation and all of its complexities (Leydon et al, 2001). Unfortunately, there is no real way of evidencing this remark in anything more than an unsatisfactory way, by again referring to the popularity of independent avenues of information and support.

Finally, it should be noted that there were some patients at H2 who felt that to have the first meeting with the Consultant immediately followed by another meeting with the Information Specialist simply meant longer in clinic, the car park cost more and life routines were held off for an hour longer than some felt necessary. Again, this illustrates rather neatly the point raised on a few occasions throughout this thesis and that is that any practice almost promises to set up some double bind (Silverman, 1987). The challenge is to strike a balance, which suits most parties, most of the time. Central to achieving this is to see what people are already doing in the consultation space and properly ask what is and is not realisable in light of what they already do.

8.4 Limitations of this thesis: An outline and a defence

> The tension between making it better and getting it done appears wherever people have work to finish or a product to get out... We want to get it done and out to the people who will use it, eat it, read it. But no object ever fully embodies its makers' conception of what it could have been.
>
> Becker, 1986: p122[20].

I am more than aware that the data chapters all too fleetingly address data so rich that each chapter could potentially have formed the foundation for the entire thesis. Moreover, any single analytic point could have been pursued in more detail. However, I was keen to show the development of what happens over the course of these meetings, from the beginning of History Taking (*Chapters Three* and *Four*), the move to diagnostic embellishment and treatment talk (*Chapter Five*) through to what treatment might or might not achieve for the patient (*Chapter Six*).

Through repeated visits to the data it was clear that members were hearably engaging in a stepwise build towards the core task of the consultations – to discuss additional treatment. I aimed to render this broader 'package' (Peräkylä, 1995) visible by showing some of the features of the work that goes into the accomplishment of this 'bigger whole'. In this sense, I took the natural unfolding trajectory of the consultation as my guide for what to include and did my best to discuss *some* of the core ways in which this unfolding is audible as 'natural'. The losses of a brief consideration of some of the devices / strategies / methods described is hopefully compensated by the gain of a broader view of treatment focussed cancer meetings.

In *Chapters One* and *Two* (Introduction and Natural History) I highlighted some of the methodological difficulties with the study presented in this thesis and conversation analytic work in general. Here, I focus on some additional limitations of this particular thesis, and in so doing (try to) avoid repeating the core limitations already outlined.

[20] Quoted in Dunleavy, 2003: p197.

8.4.1 The limits of micro-interactional work: Does size matter?

Size or lack of size is a criticism that is often levelled at qualitative research in its various forms. As mentioned in the Introduction (*Chapter One*), conversation analytic studies are ordinarily based on large data corpora. In this thesis I draw on data from a corpus of 27 audio-recordings from two hospitals and two consultants. I also drew (informally) on another data set, gathered but not all transcribed in time for this thesis. This thesis has then used a relatively small corpus and made claims based on this. Nevertheless, there are good reasons to be confident about the credibility of the research reported. I briefly sketch some of these below.

Although it is preferable to analyse much larger data sets, especially if policy makers are to be convinced by the research and to enable 'lessons to be drawn for medical practice and training' (Drew, 2001: p268; Heritage, 1999), in this study I was unable to gather and analyse a larger data set or to do systematic comparative analyses with data sets gathered by others for their own purposes. I was, however, able to turn to other published and grey literature to test the credibility of my analyses and comparisons within my own data set meant that initial analytic noticings were constantly compared across (horizontally) and within (vertically) the data set and reformulated where there were grounds for doing so (which was often) (see Seale, 1999 for a discussion of the Constant Comparative method). Initial ideas were dynamic and open to change, making every effort to falsify initial readings of the data, hence avoiding anecdotal and premature claims (Silverman, 2001: p224). As Hammersley (1992) states the reliability of a small study may be compromised, but the validity of analysis prioritised. Multiple coders clearly were not involved in this analysis (for good reason), but data workshops and the sharing of early ideas meant that the acceptability / validity and (inter-rater) reliability of initial coding could be tested before returning to the entire corpus for further analysis.

I reproduced fragments that honestly reflect the patterned regularity of phenomena present in the corpus. Where exemplary cases are cited, every effort was made to ensure that they were indeed exemplars of the phenomenon to which I referred. In the end, 'all

research however exploratory involves selection and interpretation' (Hammersley and Atkinson, 1983: p13) and I have endeavoured to select and interpret well. The losses to size or breadth are hopefully more than compensated by the gains in depth/a broader view of how the consultations (can) play out. Moreover, following Sacks' (1992) less defensive line, that something happens at all (however many times) matters, and may be worth our attention.

8.4.2 'Context: Whose context?'

> (...) [T]he concept of 'context' so far discussed is, by any standards, an exceptionally immediate and local one. The 'contexts' we have discussed thus far have comprised scarcely more than three or four turns at talk. How, it may legitimately be asked can this highly local sense of context (...) enable us to get any purchase on events which are informed by a larger, overarching context such as a social institution?
>
> Heritage, 1984: p280.

A core focus for me in this thesis has been to privilege what participants make relevant in interaction. I have tried (as far as possible) to avoid making assumptions about the talk that I came to as an analyst before getting to grips with the talk. As is hopefully clear, this approach to analysis insists on a particular conception of 'context' to make sure that observations be grounded in 'what [members] demonstrably orient to as relevant' (Schegloff, 1999a). Heritage's (1984) opening quote neatly captures the character of this conception and its potential limitation.

In the Natural History (*Chapter Two*) I briefly considered the criticisms that are often leveled at conversation analytic inspired work, where the chief goal is to focus on fine-grained interactional issues, to the 'neglect' of broader macro considerations. In that chapter I indicated that conversation analysis is not beyond considerations of context on a broader level (however defined). Rather, the in situ produced orderliness is considered the necessary *starting point* for analysis. As Silverman (1999) states:

> Structural sociologists deal with macro issues that cannot be wished away. Similarly, ethnographers and discourse analysts who insist on the relevance of understanding the social contexts of interaction are not mistaken (...). Instead, my position is that we are not faced with either/or choices but with issues largely of timing.
>
> p407.

The issue of timing Silverman (1999) refers to involves delaying 'why' questions, until the 'how' questions are properly tackled. Schegloff (1997) similarly defends a mirco-analytic understanding as the first step of analysis:

> You need to have technical analysis first, in order to constitute the very object to which critical or socio-political analysis might sensibly and fruitfully be applied.
>
> p174.

It is true that this study did not set out to comment on the organisation of cancer clinics in the broader sense, the experience of cancer or of being a doctor who treats and manages cancer patients. This is not a limitation, but a necessary addition to more macro considerations of 'clinic life'. In so doing, a range of activities were identified that might not so easily be fitted into preordained classifications. Moreover, these activities can be linked to broader considerations.

Through a local consideration of context we have seen how the 'routine' of the clinic consultations is worked at and accomplished. Specifically, for example, two chapters (*Three* and *Four*) focussed on the act of 'history taking' by drawing on techniques provided by conversation analysis and in doing so we were able to see that history taking is about so much more than is commonly or normatively conceived.

These are all critical points. In sketching (in detail) the 'how' of cancer talk, we are able to view members "everyday procedures for organising their actions in talk and constructing their worlds" (Wetherall et al., 2001: p396). In particular, we have viewed how a doctor may pursue a 'broader project' without diminishing opportunities for

patients to speak up and speak up in their own words. Further, the stepwise movement through tasks had an 'effortless feel', which, given the magnitude of the information being discussed, is remarkable. Part of this is achieved via the devices and organisations discussed. 'How to' texts or courses could capitalise on these insights to 'process', which do move us beyond such building block features as Q-A pairs[21]. For example, actions involved, 'getting acquainted' (see Svennevig, 1999), telling stories of journeys to diagnosis, moral accounting work, information sharing, invoking other players involved in patient care and more broadly paving the way to 'future oriented issues' (such as treatment and what that might or might not achieve).

Despite beginning with micro-analytic concerns we have been able to inform discussions of a broader practico-structural nature. Clear constraints on the type of turn a patient can take and when exist, but through their skilful collaboration doctors do not come across as overly-interrogational. Through close observation of the turns at talk – both composition and position – we have witnessed how the institutionality of the events is talked into being in some ways that are common to many institutional activities. Drew and Heritage (1992) suggest that the institutionality of an event may be hearable in three key ways (drawing on Levinson's discussion of Activity Types[22]):

[21] I recently returned from a conference at which a speaker was asked to distinguish his discourse analytic work of telephone calls (using Sinclair's approach) from conversation analysis. The speaker said that DA can deal with structural issues, whereas conversation analysts stay with the detail and rarely move away from considerations of adjacency pairs.

[22] "Activity Type" is described by Levinson (1992) as, "any culturally recognized activity (...). In particular, it refers to, "a fuzzy category whose focal members are goal defined, socially constituted, bounded, events with constraints on participants, setting and so on, but above all on the kinds of allowable contributions" (p68). Following a discussion, Levinson concludes, "Types of activity (...) play a central role in language usage. (...) On the one hand, they constrain what will count as an allowable contribution to each activity; and on the other hand, they help to determine how what one says will be "taken" – that is, what kinds of inferences will be made from what is said". He continues, "Both of these issues are of some theoretical and practical interest. For example, knowing the constraints on allowable contributions will be an important part of what Hymes (1962) has called *communicative competence*, the knowledge required to use language approaching in cultural situations. The inferential side to these constraints adds an important further element to our understanding of, and appreciation of, the importance of, inference in discourse. (...) having a grasp of the latter will play an important role in the reception side of communicate competence, the ability to understand what one hears" (p97-98).

1. Institutional interaction involves an orientation by at least one of the participants to some core goal, task or identity (...) conventionally associated with the institution in question.
2. Institutional interaction may involve special and particular constraints on what one or both of the participants will treat as allowable contributions to the business at hand.
3. Institutional talk may be associated with inferential frameworks and procedures that are particular to specific institutional contexts.

[Source: Drew and Heritage, 1992: p22].

In the cancer meeting discussed in this thesis, institutional contexts are 'observably and reportedly – i.e. accountably – brought into being' (Heritage, 1984: p290). For example, turn taking involves mostly doctors asking and patients answering; in terms of structural organisation, it is the doctors who open and close the meetings (with one exception in the corpus); in terms of sequential organisation, doctors produce first pair parts and initiate action; and, finally, in terms of topical organisation, doctors do (on the whole) control the topical trajectory. All of these contribute to the realisation of a broader project of establishing a common ground, and discussing and planning treatment. However, it cannot be emphasized enough that such institutionality or a degree of "pre-patterning" in discourse does not equate with the "pre-scripting of events" or moves that any one participant can make. Through turn design, for example, patients manage to attend to what is allowable in this broader scheme, while producing information that may transcend the immediate requirements of the 'institutional' task at hand. As Svennevig (1999) points out, "(...) conversationalists [do not] follow automatically a predetermined course of action. Even routines are achieved as an interactional accomplishment" (p12). Thus, we have witnessed how the medical meeting in outpatient oncology gets realised in and through a simultaneous orientation to agenda, and all that is allowable in that regard, and a combined effort of negotiation by 'active' doctors *and* patients. Starting with members' contexts allows such observations to be made, *eventually*; "we can't do everything at the same time without muddying the water" (Silverman, 1999: p 410).

8.4.3 *Another word on the limits of recorded data*

While reporting on a study of the management of patients with palliative care needs in hospital, Hak (1999) recently commented on recorded data:

> When we begin to analyse these data we are acutely aware of the fact that we have taken something from a larger whole. By beginning and finishing our recordings at given points in time we have missed what went before and what went after.
>
> p427.

It is undoubtedly the case that 'carving out' "data" on "communication" from a context of "ongoing work" is problematic (Hak, 1999). This is the case for all studies however. It is impossible to truly present and interrogate the 'ongoingness' of social life, the best we can do is tackle parts of a shifting 'whole'. Hak's particular concern was with examining the work of the consultation and neglecting the work that other participants do in other spaces. He states thus:

> The consultation is a good example of the highly planned and structured character of consultation work. This makes it relatively easy to record and analyse it, which is one of the reasons why consultants are in demand as subjects of conversation and discourse analysis.
>
> p433.

This is a real concern and, this is why I (eventually) recorded the specialist information radiographer at H2 for the later MRC funded study. To not do so did not make sense since this was an important aspect of the initial first treatment meetings. Indeed, I was acutely aware of the predictable and limited focus on Consultants whilst collecting data. It was the clinic nurses, research nurses and specialist breast, bowel and lung nurses who spent (*goal oriented*)-time with patients discussing matters 'beyond the biomedical'. Work like mine misses these moments. Thus, there ends up being a distortion of *clinic life* and of the professional health care work that gets done. A focus on the Consultant and

the clinic consultation belies the panoply of interactions along any single individuals' illness trajectory. Hak's (1999) solution to the problem of recorded data was to see recordings as "plainly wrong" and to instead return to "good old ethnography" to study the organisation of palliative care in hospitals.

Ethnography was not possible for this study and I doubt that such an approach would have yielded detailed "technical access" to the communicative project, which was the core objective of this study. In short, although Hak highlights a valid limitation of the kind of work presented here, it is difficult to be all things to all people and cover all aspects of clinic life (adequately) in a single study. I was, however, able to use my observation of clinics to help make sense of the data.

8.5 Future possibilities: What next?

The size of the corpus used for this thesis is a limitation. With only two hospitals (plus the additional hospital for the MRC study) there is scope for broadening the examination provided here to test out ideas on the additional longitudinal data gathered but not analysed. Indeed, this thesis is just a beginning. The huge benefit of the next steps of analysing the data gathered from the MRC study is the longitudinal nature of that data. A view of how the doctors and patients meet over time to discuss the treatment, how it is going, what can be hoped for in future terms and so forth may yield results that could move us even further away from the constraints of the 'bad news interview' focus and from the focus on first meetings. Maynard (2003) too has highlighted the need to conduct work that is not based purely on episodic encounters, to instead address longitudinal features of interaction (p407).

As indicated in *Chapter One*, more work is required on the gestural aspects of communication and on the role of new technologies of practice. The limits of audio data cannot be brushed under the carpet or defended too well. It is undoubtedly the case that in and through gestural moves participants can display and embody emotion, expressions of disagreement and agreement, and so forth. For example, Heath recently demonstrated:

"through their gesture and bodily comportment, patients... transpose difficulties and suffering which occur in other situations and at other times and reveal them then and there within the consultation" (WIT, Selected Papers III: p55). The role of third parties also needs to be understood; how do third parties contribute to the treatment focussed interactions (verbally and gesturally), what roles are enacted and what are the losses and gains of having a significant other or specialist nurse present in the consultation?

Spaces other than the consultation are also ripe for investigation, as Hak's (1999) critique suggests. Beach's work on telephone calls between a mother with cancer and her significant others provides tremendous insights to the broader "social milieu" of "cancer quandaries". Atkinson's (1995) work on doctors talking to doctors also provides insights beyond the space of the consultation. Indeed, Atkinson (1999) noted that most of the work on "medical discourse has focussed on the medical consultation" (p75) and there is a need for work in other settings.

Not only has this thesis focussed on cancer consultations to the exclusion of other 'spaces' or interactional places, but also it has focussed on UK based consultations. There is growing evidence to suggest that practices might vary according to country of practice (Mystakidou et al., 2005; Phungrassami et al., 2003; Fallowfield and Jenkins, 2004; Thomsen et al. 1993, Hy Wu, 2002). According to the evidence, doctors from developed countries are, for example, less likely to withhold unfavourable information to patients; for example, disclosure is found to be low in Japan and in Italy (Fallowfield and Jenkins, 2004: p313). In some countries (e.g. Greece, Singapore) it has been reported that the role of families, disclosure to families and decision-making on behalf of patients may be pivotal and families may dissuade full disclosure (Mystakidou et al, 2005; Hy Wu, 2002). If this were the case, despite the limits of the consultation space focus, the role of significant others in the consultation would provide a potentially rich comparative resource for conversation analytic work.

It might also be worth taking a practice identified in this thesis (and elsewhere), such as a predilection towards optimistic framings, and testing out this observation in settings

where different patients with different prognostic profiles are known and are consulting. Fallowfield and Jenkins (2004) survey of 3,000 doctors found that they reported their "performances" to be worse when discussing palliative care issues compared to discussing potentially curative treatment. These findings from other sources could fruitfully inform sampling for further work, to discern whether such 'face sheet variables' and broader socio-cultural matters can be demonstrated *in* practice.

Comparative studies could also usefully take forward some of the observations contained within this thesis to test them out in other non-medical sites. As Drew (2003) has pointed out it is important to resist the assumption that observations can be "attributed to the particular organizational features and exigencies associated with [a] particular setting" (p293). Peräkylä (1995) observes that much of what we see in clinic meetings originates from ordinary conversation. Indeed, as already noted, seeking other perspectives (using the PDS) is not unique to the cancer clinics analysed, but is similar to pre-sequences found in conversation (Peräklyä, 1995; Maynard, 2003). The general organisation / preference / inclination towards the relatively good or positive is not unique to cancer clinics, this has been suggested by ethnographic and empirical examinations in other medical settings (Maynard, 2003) and, as stated, has been found to be the case between lay members (Beach, 2003).

My time in clinic provided valuable foundational knowledge and understanding of the broader organisation of patient care. A fascinating aspect of all of this is the now compulsory multidisciplinary team meeting (MDTs). This is a space where all of the key (professional) players in patient care meet to discuss 'cases' and agree on treatment / management disposals. A smaller longitudinal focus on a sample of patients, where a combination of patient–doctor meetings, 'family' interactions and multidisciplinary meetings were recorded could provide an empirical aperture into a broader slice of individual patient trajectories and all of the complexities therein. The challenge of drawing sensible conclusions based on data gathered at different temporal moments would be great, but the pay off in terms of moving beyond snap shot views from one particular 'site' towards multiple sites over time renders this an interesting challenge.

8.6 A final word

> ...[T]here is a hammer, pliers, a saw, a screwdriver, a ruler, a glue-pot, nails and screws. The functions of words are as diverse as the functions of these objects.
>
> Wittgenstein, 1953.

I have looked at *some* of the functions of *some* of the features noted in talk-in-interaction collected for this thesis, there is still so much more that could be said. I have described *some* of the possibilities for communicating in the cancer clinic. None are engraved in stone. Rather, each device / strategy / practice is changeable and entirely context bound. For example, Schegloff (1993) states:

> [P]roducing a continuer after talk that is intendedly complete (after the point of a story or the thrust of an argument, for example...) can do the precise *opposite* of sociability – it can show *in*attention, failure to grasp the other's point, or failure to align oneself interactionally with its thrust.
>
> p106.

In this vein, I have aimed to use the insights of other conversation analytic work, but have done so without 'blindly' counting instances of previously conceived ideas (like the Perspective Display Invitation) and casually laminating these onto my data, with no consideration for function, position or composition.

Lessons to take away from this thesis must include the partnership involved in making these meetings happen. Patients and doctors work *and* work in concert. Moreover, despite the methodological debates, combative cultures and so forth, there is a great synergy between the interview based research ('hope' and 'positivity combined with honesty') and communications research based on categorisations (a stepwise build, the advice to "ask before you tell" and so forth). The key is to somehow (continue to) make connections clear between these different evidences and elaborate upon and support each other's work with no loss of validity or depth.

In terms of understanding the cancer *experience* (for doctors and patients), this thesis contributes to a vast literature, but as Beach (and Hopper) note there is still much to learn in- and out-side of the cancer clinic.

> It is obvious and compelling (...) that the full social milieu of cancer quandaries, involving "what communicators do, not what scholars have validated" (Hopper, 1981: p 209), remain largely unearthed and thus taken-for-granted.
>
> Beach, 2003: p192.

APPENDICES

APPENDIX I – PATIENT CONSENT FORM

Patient Information Study – Patient Consent Form
TO BE COMPLETED BY THE PATIENT

Patient Name:

Please read the statements below.

Circle 'YES' if the answer is yes or 'NO' if the answer is no.

1.	I have been given a complete explanation of the study and had the opportunity to ask questions	YES	NO
2.	All of my questions have been answered	YES	NO
3.	I understand that I may withdraw from the study without the need to explain why.	YES	NO
4.	I understand that withdrawing from the study will not affect my future care.	YES	NO
5.	I understand that my help will be anonymous; what I say will not be connected to my name.	YES	NO
6.	I agree to take part in the Patient Information Study	YES	NO
7.	I agree to have my consultation(s) recorded	YES	NO

If you are happy to take part and to have your consultation(s) recorded, please sign below.

Signed: ---------- Date: ----------

I would like a copy of the tape recording sent to me	YES	NO

Office Use Only (below this line)

I have explained the Patient Information Study to the above patient and s/he has / has not agreed to take part. Signed: Date:

Appendix II - PATIENT INFORMATION SHEET

[HOSPITAL AND TRUST DETAILS INSERTED HERE]

The Patient Information Study - Consultation Recordings

Why are we doing this study?

An important aspect of care for people with cancer is the provision of information and support. We are conducting this study to find out about the information and support available to patients, what works well and what could be made better.

What will you be asked to do?

If you do agree to help us you will be asked to:

1. Fill out a short questionnaire, which might take five or ten minutes of your time.
2. Have your next consultation audio-recorded and, if you agree, the next few consultations you have at the hospital oncology department recorded.

Who are we?

We are a research team based at the London School of Hygiene and Tropical Medicine (part of the University of London). The Economic and Social Research Council fund our research.

Thank you

We do hope that you will be able to help us with our study. Any information you give us will remain confidential to the study and will not be shared with other doctors or patients. Nothing you say will be connected to your name, it will be anonymous.

You do not have to take part in this study. If you do agree to take part and want to withdraw at a later stage, you may do so at any time without the need to explain why. Any information that you had given us prior to your withdrawal would be destroyed and not used in the study. Whether you decide to help us with this study or not, your care will be exactly the same.

Thank you very much for your help.

Any questions?

If you have any questions please call Geraldine on [number] or write to G. Leydon, [address].

APPENDIX III – SOME BACKGROUND PATIENT INFORMATION

ESRC DATA

	H1	H2
Cancer		
Bowel	10	0
Breast	3	0
Head / Neck	1	13
	14	**13**

	H1	H2
Gender		
Male	9	13
Female	5	0
	14	**13**

	H1	H2
Met before		
Yes	1	10
No	13	3
	14	**13**

	H1	H2
Started treatment		
Yes	0	3
No	14	10
	14	**13**

Note: MRC data = seven from London teaching hospital and six from midlands hospital. Further details not yet tabulated and majority not used in this thesis. All patients used in this thesis had not met the consultant previously and all had breast cancer.

APPENDIX IV – TRANSCRIPTION CONVENTIONS

The conventions shown below are taken from Paul ten Have (Doing CA: A Practical Guide, 1999), most are developed by Gail Jefferson (see 1989: 193-6) and are commonly used by conversation analysts. The conventions are used to record the details of verbal speech produced in interaction. Differing levels of utilisation of such conventions are common, depending on the aim of the research and the intended audience of the research.

Sequencing

[	*A single bracket* indicates the point of overlap onset.
]	*A single bracket* indicates the point at which an utterance or utterance-part terminates vis-à-vis another.
=	Equal signs, one at the end of one line and one at the beginning of a next, indicate no 'gap' between the two lines. This is often called latching.

Timed intervals

(0.0)	*Numbers in parentheses* indicate elapsed time in silence by tenth of seconds, so (7.1) is a pause of 7 seconds and one tenth of a second.
(.)	*A dot parentheses* indicates a tiny 'gap' within or between utterances.

Characteristics of speech production

Word	*Underscoring* indicates some form of stress, via pitch and/or amplitude
::	*Colons* indicate prolongations of the immediately prior sound. Multiple colons indicate a more prolonged sound.
-	A *dash* indicates a cut-off.
.;??	*Punctuation marks* are used to represent characteristics of speech production, especially intonation; they are not referring to grammatical units.
.	A *period* indicates a stopping fall in tone.
,	A *comma* indicates a continuing intonation, like when you are reading items from a list.

?	A *question mark* indicates a rising intonation.
↑↓	*Arrows* indicate shifts into higher or lower pitch in the utterance-part immediately following the arrow.
WORD	*Upper case* indicates especially loud sounds relative to the surrounding talk.
°	Utterances or utterance parts bracketed by *degree signs* are relatively quieter than the surround talk.
<fast> >slow<	*Right left carets* bracketing an utterance or utterance part indicate speeding up or slowing down of the bracketed words. It should be noted that in this thesis the clarets are used in the opposite way to their conventional usage (i.e. >fast<, <slow>).
.hhh	A *dot-prefixed row of* hs indicates an inbreath. Without the dot, the hs indicate an outbreath.
W(h)ord	A *parenthesised* h, or a *row of* hs *within a word* indicates breathiness, as in laughter, crying etc.

Transcriber's doubts and comments

( )	*Empty parentheses* indicate the transcriber's inability to hear what was said. The length of the parenthesised space indicates the length of the untranscribed talk. In the speaker designation column, the empty parenthesis indicates inability to identify a speaker.
(word)	*Parenthesised words* are especially dubious hearings or speaker identifications.
(( ))	*Double parentheses* contain transcriber's descriptions rather than, or in addition to, transcriptions.

Appendix V - Data used in Chapters 3., 4., 5. and 6.

Ch. 3: History-Taking Part I	Hospital	Case Number
3.3: Move to business		
Extract 3.1	H1	1
Extract 3.2	H1	2
Extract 3.3	H2	3
Extract 3.4	H2	4
3.4.1: Closed Questions		
Extract 3.1	H1	5
Extract 3.2	H1	6
Extract 3.3	H1	2
Extract 3.4	H1	10
3.4.1.2: The Responses		
Extract 3.1	H1	5
Extract 3.2	H1	6
Extract 3.3	H1	2
Extract 3.3a	H1	2
Extract 3.4	H1	10
3.4.2: Open Questions		
Extract 3.1	H3	11
Extract 3.2	H1	12
Extract 3.3	H3	13
Extract 3.4	H1	14
3.4.2.1: The questions		
Extract 3.1	H3	11
Extract 3.2	H1	12
Extract 3.3	H3	13
3.4.2.2: The responses		
Extract 3.1a	H3	11
Extract 3.2a	H3	13
Extract 3.3a	H1	12
Extract 3.4a	H1	14
Footnote:	*H1*	*Case A.*

Ch. 4: History-Taking Part II	Hospital	Case Number
4.3: Examining the Open Question		
Extract 4.1	H1	1
Extract 4.2	H1	2
Extract 4.3	H1	1
Extract 4.4	H1	2
Extract 4.5	H1	3
4.3.2: Patient answers and doctor responses		
Extract 4.6	H1	4
Extract 4.7	H1	5
Extract 4.8	H2	6
Extract 4.9	H1	7
Extract 4.10	H1	8
4.4: Summative knowledge proposals		
Extract 4.11	H1	9
Extract 4.12	H1	10
Extract 4.13	H2	11
Extract 4.14	H2	12
Extract 4.15	H1	13
Extract 4.16	H1	14
Extract 4.17	H1	2
Extract 4.18	H2	15
Footnote:		

Ch. 5: Giving Evidence	Hospital	Case Number
5.3: The logical build towards treatment talk		
Extract 5.1a	H1	1
Extract 5.1b	H1	1
Extract 5.1c	H1	1
Extract 5.2a	H1	2
Extract 5.2b	H1	2
Extract 5.2c	H1	2
Extract 5.3a	H2	3
Extract 5.3b	H2	3
Extract 5.3c	H2	3
5.4: Invoking the voice of medicine		
Extract 5.4	H1	2
Extract 5.5	H1	4
Extract 5.6	H2	5
Extract 5.7	H1	6
Extract 5.8	H1	1
Extract 5.9	H2	7
Extract 5.10	H1	1
Footnote:	H1	Case A

Ch. 6: Good/bad/uncertain	Hospital	Case Number
6.3.1: Introducing the pairing phenomenon		
Extract 6.1	H2	1
Extract 6.2	H2	1
Extract 6.3	H3	2
6.3.3: Introducing uncertainty		
Extract 6.4	H2	3
Extract 6.5	H1	4
Extract 6.6	H2	5
Extract 6.7	H2	1
Extract 6.8	H2	5
Extract 6.9	H1	6
Extract 6.10	H1	7
Extract 6.11	H2	5
6.4.1: Patient uptake: Marking good news		
Extract 6.12a	H2	5
Extract 6.12b	H2	5
Extract 6.13	H2	1
Extract 6.14	H1	8
Extract 6.15	H1	8
6.4.2: Patient uptake: Beyond stoicism		
Extract 6.16	H1	9
Extract 6.17	H3	10
Extract 6.18	H1	11
Footnotes:		
	H3	Case A.
	H2	Case B.

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'DIVIDING THE DESOLATION': CLIENTS VIEWS ON THE BENEFITS OF A CANCER COUNSELLING SERVICE

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When I came to BACUP [now CancerBACUP], I felt totally out of control—counselling helped me to find a 'centre' again. There was immense value in the 'confessional' elements of the sessions—I could be totally honest in a totally non-judgemental environment. At the end of the day, however, no amount of talking can change the basic situation—terminal disease isolates. There are no solutions but counselling is the only means I have found to 'divide the desolation' and I am grateful for the experience (woman with cancer).

SUMMARY

This paper describes clients' accounts of the benefits they derived from a short course of cancer counselling provided within a humanist framework. Three hundred and two clients who had attended at least one session of a short course of cancer counselling received an evaluation form, which incorporated both fixed-choice and open-ended questions. One hundred and forty two (47%) clients returned evaluation forms; those who had attended more sessions were significantly more likely to do so. Quantitative data were analysed using Statistical Package for the Social Sciences (SPSS) for Windows and qualitative data using a thematic approach. Almost all clients indicated that they felt they had benefited from counselling. Analysis of the open-ended questions identified nine main benefits of counselling and four key avenues or processes through which clients derived these benefits. Overall, counselling was seen as helping them to work through powerful thoughts and feelings and so to come to terms with cancer and to regain a sense of control in their lives. The benefits of a short course of counselling which clients identified reflect the aims of humanistic counselling which are not well captured by psychiatric assessments or most standard research instruments. In evaluating cancer counselling services, assessments which include these client-defined outcomes may provide a more sensitive way of gauging the value of counselling to a non-clinic population. Copyright © 2001 John Wiley & Sons, Ltd.

INTRODUCTION

It is now generally acknowledged that the diagnosis of cancer is a stressful life event which can give rise to marked psychological distress in both the patient (Derogatis *et al.*, 1983; Greer *et al.*, 1992; Zabora *et al.*, 1997) and their close relatives and friends (Harrison *et al.*, 1995; Toseland *et al.*, 1995; Harris, 1998). Farrington (1994) describes the typical sequence of crisis reaction as involving initial shock and disbelief, followed by anxiety, anger, guilt and depression. For a minority of patients, distress may be at a sufficiently high level to constitute a psychiatric disorder; for the rest, it may be regarded as a normal response to a major life crisis (Alderson *et al.*, 1993). Whatever their clinical state, however, increasing numbers of cancer patients and their relatives and friends look to counselling (along with other psychosocial interventions) for help and support in dealing with the distress associated with cancer (NHS Executive, 1996).

The increase in demand for counselling services has, in turn, generated a number of studies to

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evaluate their effectiveness. There is clear evidence to suggest that psycho-social interventions have positive benefits for clients, including a significant reduction in psychological morbidity, less pain and physical symptoms and fewer maladaptive coping responses (Linn *et al.*, 1982; Greer, 1995; Marchioro *et al.*, 1996; Moorey *et al.*, 1998). The value of counselling interventions, including supportive-expressive psychotherapy, has been demonstrated in relation to a range of clients, including highly distressed women with breast cancer (Spiegel *et al.*, 1999) and individuals with a genetic predisposition to cancer (Esplen *et al.*, 1999). Meta-analyses of high-quality, randomised control trials have provided, perhaps, the most convincing evidence regarding the value of psychological interventions more generally. In an analysis of 62 treatment–control comparisons, Meyer and Mark (1995) found significant beneficial effect sizes for four of the five summary outcome categories they used. More recently, Shear and Maguire (1999) conducted two further meta-analyses of trials of psychological interventions, 25 using anxiety as the main outcome measure and 20 using depression. They concluded that preventative psychological interventions have a moderate clinical effect upon anxiety (but not on depression), and that interventions targeted at those at risk or suffering significant distress have stronger clinical effects.

While the number of studies of the outcomes of psycho-social interventions continues to increase, the preference for randomised control trials as the design in clinical research has meant that virtually all these studies have focused on researcher-defined outcomes and have used standard quantitative instruments to measure them. It is clearly important that the outcomes of counselling be measured in a way that allows the clinical effectiveness of counselling to be assessed. However, an *exclusive* focus on such measures overlooks an important dimension of the outcomes of care: the benefits which clients themselves perceive they derive from counselling. An understanding of the client's perspective is essential to a full appreciation of the value of counselling. This may be particularly important in relation to clients who do not have a clinical psychiatric illness, and who can, therefore, show little improvement following counselling in terms of standard quantitative measures (Reele, 1994; Watson *et al.*, 1996). Such individuals—who may include cancer patients, as well as their relatives and friends—may nonetheless experience considerable distress in relation to cancer and may gain considerable benefit from specialist counselling. Very little is known, however, about how clients experience counselling or how they view its benefits (Schou and Hewison, 1999).

This paper describes the findings of a study which explored clients' own accounts of the ways they benefited from a brief course of counselling. It is part of a broader evaluation of a cancer counselling service which has sought to establish who used the service and how they evaluated it (Boudioni *et al.*, in press). The aim of this paper is to identify the benefits they derived from counselling and the avenues or processes through which they derived them.

METHODS

The counselling service

The study was carried out as part of an evaluation of the free cancer counselling service provided by CancerBACUP (formerly BACUP), an independent charity which provides information and support to those affected by cancer. Counselling in this context was defined as 'the skilled and principled use of relationships to facilitate self-knowledge, emotional acceptance and growth, and the optimal development of personal resources' (British Association of Counselling, 1989). The cancer counselling service aimed to help people affected by cancer to resolve the difficulties that living with cancer brings.

Individuals who contacted the service were spoken to on the telephone to establish that they met the criteria for the service: people with concerns related to cancer, not considered suicidal, fit enough to travel to central London and living close enough to make the journey. Where the counselling service was appropriate, clients were offered a contract of eight face-to-face counselling sessions of 50 min each. For a brief period, this was reduced from eight to six sessions. As there was a great demand for the free service, clients were offered only one short course of counselling. However, information on other sources of counselling was made available and, when appropriate, counsellors recommended another counselling agency to their clients. A very small number of clients were offered additional sessions.

All 21 counsellors who provided the service over the period of the study had a British Association of Counselling (BAC) or other accreditation and at least one year's post qualification experience of counselling. Some were employed by CancerBACUP, and many others worked voluntarily. All were in personal therapy and had clinical supervision following BAC guidelines. They worked broadly within a humanistic framework, but used one of a number of different models, including Gestalt, person-centred, and transactional analysis.

The relatively large number of individuals who provided the CancerBACUP counselling service and the range of models they used inevitably meant that there was some variation in the nature of the counselling offered to clients in this study. However, all counselling was within the humanistic tradition, and shared a common set of values and approach. Humanistic counselling is distinctive amongst psychological interventions in its focus on the experience of the individual or the individual's own perceptions. This is in contrast to the external focus of psychodynamic and behavioural frameworks (Rogers, 1959; Davis and Fallowfield, 1991). Carl Rogers, the 'father' of the humanistic theory of counselling, emphasised the importance amongst counsellors of empathy, genuineness and unconditional positive regard for the client. Roth and Fonagy (1996, p. 9) describe the role of the therapist within supportive and experiential therapies, including humanistic counselling, as that of a 'facilitating observer, who will aid clients in extending their awareness of their subjective world'. Clients, in turn, 'are offered support in their natural striving towards self-determination, personal meaning and self-awareness.'

The evaluation

For the evaluation of the counselling service, data were collected on all clients for whom an appointment was booked at the CancerBACUP counselling service during an 18-month period. Demographic data were collected by the service co-ordinator, who completed a client data sheet at the time the appointment was booked. Information on client type, age and gender were collected during the whole 18-month period. For the first 12 months, information was also collected on occupation and employment status; for the last 5 months, additional information was collected on cancer type.

Clients who attended at least one counselling session received an evaluation form with a prepaid return envelope after their last session. Forms were sent out as soon as possible after their last session; when clients finished before the end of the contracted sessions, the form was sent out as soon as it was confirmed that they would not attend again. Consent to the study was given by returning the evaluation form. The evaluation form incorporated both fixed-choice questions, which required clients to indicate their views on a 4-point Likert-type scale, and open-ended questions, which asked clients to give an account of their experience in their own words. The fixed-choice questions are set out in Table 2. Information from the client data sheet and answers to the fixed choice questions on the client evaluation form were entered onto a PC for analysis, using Statistical Package for the Social Sciences (SPSS) for Windows. Likert scales were converted into dichotomous variables for analysis by combining the two positive and two negative scale points.

Four open-ended questions were also asked: (1) Was counselling as you expected it to be? If yes, in which ways? If no, in which ways did it differ from what you expected? (2) With which areas/problems did the Service help you? (3) What changes, if any, have you made as a result of the counselling? (4) Please take this opportunity to express you feelings, either positive or negative, about your experience with BACUP's counselling service. Please could you be completely open since this is the only way we can evaluate ourselves. Responses to these open-ended questions were analysed by Mary Boulton and Markella Boudioni according to the methods of inductive analysis used in qualitative research (Fitzpatrick and Boulton, 1994). Responses ranged from one line to several pages of hand-written text; the most common response was a short paragraph of two or three sentences after the questions. However, in their responses, clients did not generally confine themselves to the specific question asked, nor did they provide a separate reply to each question. Instead, they took the opportunity provided by the evaluation form as a whole to convey their views on the cancer counselling they had received.

The analysis of the responses to the open-ended questions was carried out in two stages. The completed evaluation forms were first divided into two equal groups, and the responses written on

the forms in the first group read repeatedly to begin to identify the key themes and categories. Two main themes were identified, relating to what clients described as (1) the main types of benefits or outcomes of counselling, and (2) the avenues or processes through which they derived these benefits. Within each theme, a number of substantively different categories were distinguished and developed into coding categories. These categories were then used to code the second group of evaluation forms; no new categories were identified at this stage. When all the evaluation forms were coded, the relationship between themes and categories was explored.

RESULTS

Characteristics of sample

A total of 384 individuals booked an appointment over the 18-month period. Their demographic characteristics and use of the counselling service are described in another paper (Boudioni *et al.*, in press). Of these, 302 attended at least one counselling session and received an evaluation form. A completed evaluation form was returned by 142 (47%) clients; their characteristics are shown in Table 1. Those who returned the questionnaire did not differ from those who did not in terms of type of client, gender, age, employment status, social class or cancer type. However, the probability of return was greater for clients who had completed more sessions ($\chi^2 = 22.572$, df = 3, $p = 0.000$).

Perceived benefits from counselling

To what extent did counselling help? Clients' ratings on fixed-choice scales. The great majority of clients who returned the evaluation form felt that they had benefited from the counselling service (Table 2). In response to the fixed-choice questions, over 90% indicated that their emotional health was better at the end of the counselling sessions; almost as many indicated that the reason they had gone for counselling had been dealt with and that counselling had helped them cope with their situation. Similarly, over 95% indicated that they would return to the counselling service if they needed further help and would recommend it to others.

No statistically significant differences in their replies were found by client type, gender employment code or social class. However, clients who attended three or more sessions had a more positive experience overall (Table 2): significantly more reported poor emotional health before counselling and better health after it; felt the reason they had gone for counselling had been dealt with and that the counselling helped them to cope with their situation; and would return to the Counselling Service if they needed further help. In addition, significantly more clients who were 49 years old or less felt that counselling helped them to cope with their situation compared with those clients aged 50 or more years (88.5% vs 72.2%; $\chi^2 = 5.212$, df = 1, $p = 0.032$).

How did counselling help? Clients' responses to open-ended questions. The views and experience which provide the context for these assessments were elaborated more fully in the replies clients wrote to the open-ended questions. Clients described a wide range of feelings in response to cancer – including anger, fear, grief and guilt – as well as the strains these emotions created in their personal relationships. Counselling helped them deal with these in a number of ways. These are described in the rest of this section, under four main headings. These headings refer to what clients identified as the four main avenues or processes through which they derived benefits from counselling: expressing feelings, examining and understanding emotional responses, confronting the fear of death, and working through powerful thoughts and feelings. What clients identified as the benefits of counselling – gaining emotional relief, realising their feelings were 'normal', freeing them to give greater attention to their own emotional needs, improving their ability to communicate with others, enabling them to attend to the needs of others, accepting their diagnosis, feeling less alone, coming to terms with cancer and recovering a measure of control in their lives – are then elaborated under each of these headings.

Expressing feelings: The simplest way in which counselling helped clients was by providing a time and place for them to talk about themselves and their response to cancer. For many clients, even those with close family and friends, this was difficult in the normal course of their lives. Some were simply not used to expressing their feelings openly:

Table 1. Socio-demographic characteristics of clients who attended at least one session and were sent evaluation forms (percentages given in parentheses)

	All clients who attended at least one session		Evaluation forms returned		Evaluation forms not returned	
Number of sessions attended	$n = 302$		$n = 142$		$n = 160$	
1–2	82	(27.1)	22	(15.5)	60	(37.5)
3–5	55	(15.2)	24	(16.9)	31	(19.4)
6–7	63	(20.9)	37	(26.1)	26	(16.3)
8+	102	(33.8)	59	(41.5)	43	(26.9)
		(100.0)		$\chi^2 = 22.572$	df = 3	$p = 0.000$
Type of client	$n = 302$		$n = 142$		$n = 160$	
Person with cancer	138	(45.7)	67	(42.2)	71	(44.4)
Relative/friend	164	(54.3)	75	(52.6)	89	(55.6)
		(100.0)		$\chi^2 = 0.139$	df = 1	$p = 0.485$
Gender of client	$n = 302$*		$n = 142$*		$n = 160$*	
Male	65	(21.9)	33	(23.7)	32	(20.2)
Female	232	(78.1)	106	(76.3)	126	(79.7)
		(100.0)		$\chi^2 = 0.342$	df = 1	$p = 0.485$
Missing	5		3		2	
Age of client	$n = 302$*		$n = 142$*		$n = 160$*	
≤29	45	(15.7)	16	(12.1)	29	18.16
30–39	105	(36.7)	49	(37.1)	56	36.4
40–49	69	(24.1)	31	(23.5)	38	24.7
50–59	43	(15.0)	23	(17.4)	20	13.0
60+	24	(8.4)	13	(9.8)	11	7.1
		(100.0)		$\chi^2 = 3.670$	df = 4	$p = 0.452$
Missing	16		10		6	
Employment status	$n = 221$*		$n = 100$*		$n = 112$*	
Employed	154	(72.5)	76	(71.7)	78	(73.6)
Other	58	(27.4)	30	(28.3)	28	(26.4)
		(100.0)		$\chi^2 = 0.024$	df = 1	$p = 0.878$
Missing	9		3		5	
Social class of client	$n = 221$*		$n = 100$*		$n = 112$*	
I and II (professional, managerial and technical occupations)	122	(75.3)	63	(79.7)	59	(71.1)
III (NM) (skilled non-manual occupations)	30	(18.5)	12	(15.2)	18	(21.7)
III (M), IV and V (skilled manual, partly skilled and unskilled occupations)	10	(6.2)	4	(5.1)	6	(7.2)
		(100.0)		$\chi^2 = 1.643$	df = 2	$p = 0.440$
Unclassified	50		27		23	
Missing	9		3		6	
Cancer type	$n = 88$		$n = 38$		$n = 50$	
Breast	22	(25.0)	10	(26.3)	12	(24.0)
Lymphatic/haematological	16	(18.2)	8	(21.1)	8	(16.0)
Other	50	(56.6)	20	(52.6)	30	(52.6)
		(100.0)		$\chi^2 = 0.554$	df = 2	$p = 0.758$

* All missing data are recorded; however, the percentages are calculated on the basis of known and classified data only for ease of interpretation.

The Pearson and likelihood ratio Chi-squares for independence have been calculated with Yate's correction and Fischer's exact test, where necessary.

Table 2. Perceived benefits and satisfaction from counselling (percentages given in parentheses)

	All clients who returned evaluation forms		Number of sessions attended			
			1–2		3+	
	$n = 142$		$n = 22$		$n = 120$	
How would you have rated your emotional health/ well being—before you started counselling?						
Poor*	122	(85.9)	14	(63.6)	108	(90.0)
Good*	20	(14.1)	8	(36.4)	12	(10.0)
		(100.0)		$\chi^2 = 6.661$	df = 1	$p = 0.004$
How would you have rated your emotional health/ well being—at the end of your counselling sessions?						
Worse*	13	(9.2)	8	(36.4)	5	(4.2)
Better*	129	(90.8)	14	(63.6)	115	(95.8)
		(100.0)		$\chi^2 = 19.464$	df = 2	$p = 0.000$
Do you think the counselling you received helped you cope with your situation/problem differently?						
Yes*	120	(84.5)	8	(36.4)	112	(93.3)
No*	22	(15.5)	14	(63.6)	8	(6.7)
		(100.0)		$\chi^2 = 41.838$	df = 1	$p = 0.000$
Do you feel the reason you came to Cancer-BACUP's counselling service was dealt with?						
Yes*	126	(88.7)	13	(59.1)	113	(94.2)
No*	16	(11.3)	9	(40.9)	7	(5.8)
		(100.0)		$\chi^2 = 19.504$	df = 1	$p = 0.000$
If you needed further help, would you return to the CancerBACUP counselling service?						
Yes*	129	(95.6)	15	(71.4)	114	(100.0)
No*	6	(4.4)	6	(28.6)	0	(0.0)
		(100.0)		$\chi^2 = 27.691$	df = 1	$p = 0.000$
Missing	7					
Would you recommend the counselling service to another person?						
Yes*	137	(96.5)	20	(90.9)	117	(97.5)
No*	5	(3.5)	2	(9.1)	3	(2.5)
		(100.0)		$\chi^2 = 0.833$	df = 1	$p = 0.171$

The 4-point Likert scale was collapsed in two broad points representing positive and negative.
The Pearson and likelihood ratio Chi-squares for independence have been calculated with Yate's correction and Fischer's exact test, where necessary.

> The counselling opened my emotional 'box' and let out many of my hidden emotions. It was hard to express how I felt and I needed lots of prompting (woman with cancer).

Others felt inhibited in opening up to those they lived with:

> An outlet for my thoughts and feelings relating to my condition, which were not always appropriate to discuss with other people (woman with cancer).

What counselling provided for these clients was the opportunity to express themselves freely and without concern for the consequences:

> It enabled me to verbalise my feelings and I was able to say exactly how I felt without fear of upsetting someone (female relative).

> I was able to say things that I could not say to anyone else and thereby get them out of my system (woman with cancer).

The *emotional relief* they experienced in doing so could be enormous and was seen as an important outcome of counselling in its own right:

> I felt as if a weight had been lifted. I suddenly had more energy and have felt far less tired since (woman with cancer).

> I could talk and get things off my chest (female relative).

Examining and understanding emotional responses: A second way in which counselling helped clients was by helping them to examine and understand their thoughts and feelings (and those of their family and friends). Clients saw this as a key feature of counselling and valued their individual counsellors for the skills they brought to bear on it.

> When I started counselling I was extremely confused following my mother's death. It helped me to begin to think it through and try to understand my grief (female relative).

> Helped me understand my emotions. Enabled me to see why I had reacted/behaved in a particular way (male friend).

In the course of examining their responses, clients came to realise—or be reassured—that *their feelings were 'normal'* or 'understandable' in the circumstances. This, too, was experienced as a great relief:

> To realise how I was feeling was OK and quite normal in the situation (male person with cancer).

> Reassurance that the 'madness' I was experiencing is a common part of grieving (female relative).

For relatives and friends of cancer patients, counselling also helped them to accept the 'legitimacy' of their feelings and to *give greater attention to their own emotional needs*:

> I am able to have compassion for myself and allow myself to be scared/upset/in a mess (female relative).

> It helped me to give myself more consideration than I had been doing (male relative).

For both cancer patients and their relatives and friends, an important consequence of this acceptance of the normality of their responses and the legitimacy of their own emotional needs was a greater openness about their feelings and a better *ability to communicate with others*:

> Mainly minor changes and a more defined and better communication with my wife (male relative).

> I have made a start by opening up more to friends and family (female relative).

Amongst relatives and friends in particular, a second consequence was also evident. By helping them deal with their own emotional turmoil, their insights into their responses to cancer also enabled clients to *attend to the needs of others*. On the one hand, it meant that they felt more tolerant and understanding of the needs of those with cancer:

> I'm more tolerant of the differences my husband and I have in our relationship (female relative).

> I am more accepting of my husband's illness and feel less negative and get less emotional when talking to the boys about it so we are able to discuss things without generating unnecessary tensions (female relative).

On the other hand, it also meant that they had the energy and composure to look after them:

> It made me realise that the problems I talked about were genuine and helped me to feel less guilt about the way I dealt with them. Helped me to rationalise and give my mother more practical support than I otherwise would have if my emotions had been allowed to overwhelm me (female relative).

> I came to counselling feeling that I was not helping my daughter enough as my distress could be adding to her burden. I feel reassured that I can continue to do my very best to help her (female relative).

Confronting the fear of death: For those clients who had cancer themselves, the diagnosis had implications which it did not have for friends and relatives. Cancer patients described a third and particularly intense way in which counselling helped them, by supporting them as they confronted their fears of death:

> I found the service to be a real lifesaver. It has been very important to me to be able to talk through subjects like death, which I found impossible to talk about with my partner and family (woman with cancer).

> Discussing death and feeling more comfortable about how I feel about death. I'm better at being positive and feel more able to deal with whatever is thrown at me (woman with cancer).

Working through their feelings in this way helped them to come to an *acceptance of their diagnosis* and its likely outcome:

> Coming to terms with the shock of having cancer and facing up to the reality of death—realising one is not invincible (woman with cancer).

> I accepted what I was trying to deny and became more focused (woman with cancer).

Just as important for the clients, counselling also enabled them to share the burden of their diagnosis and to *feel less alone* in their suffering:

> The cancer experience can seem very isolating and also becomes the centre of your world. The regular counselling sessions helped keep it in perspective (woman with cancer).

> [It helped me] to be more positive, to not feel so alone in my illness and also be more confident in dealing with family/friends and medical staff (man with cancer)

Working through powerful thoughts and feelings: On a broader level, clients—both cancer patients and their friends and relatives—saw counselling as helping them by enabling them to 'work through' the very powerful thoughts and feelings that cancer evokes in them and those around them. They described the outcome of the process of expressing, confronting and understanding their emotional responses as *coming to terms with cancer*. For many, this was the outcome of counselling that they had looked for:

> Coming to terms with my husband's illness after a year and helping me understand my reaction to it (female relative).

> Coming to terms with the sense of loss. Recognising my own feelings and not feeling guilty (female friend).

By supporting them as they 'worked through' their feelings, counselling had helped clients to accept what was happening and to face the future with less distress.

For those who had been particularly disturbed by the diagnosis, the process of working through their responses was felt to have helped them deal with their problems and to *recover a measure of control* in their lives:

> I had a feeling of inevitable doom and the fact I had cancer was too huge and overwhelming to cope with. I feel more positive. I believe my cancer experience can be put into the past eventually. I feel I have taken back some control of my life (woman with cancer).

> [Counselling] has enabled me to start thinking and planning positively my own future. This was something that I had not been able to do for over two years [since her mother died]. The feeling of a suspended state has now gone (female relative).

For some, this renewed sense of control came out of a major reassessment of their lives and the direction that they wanted it to take which counselling had made possible:

> I had breast cancer removed when I was on a year's leave. I made a good recovery but when the time came to return to my very demanding and stressful job at the end of the year, I felt that I needed to think through the direction in which my life was going and the implications which cancer has had for it. That was why I sought counselling and it was extremely helpful in enabling me to feel clear about a number of decisions (woman with cancer).

For others, it was expressed in more limited but observable steps towards change:

> The sessions spurred me to move house as my current situation was becoming intolerable (woman with cancer).

> Trying to look at different ways of earning a living—i.e. doing work that is more life-enhancing and living a life that is more life-enhancing (woman with cancer).

More commonly, however, this greater sense of control was described in terms of an altered attitude to life, involving greater confidence in themselves and a more positive approach to the future:

> I am more at ease with myself and more confident about how I deal with my cancer. I use my thinking time more constructively (female relative).

> Helping me to clarify and define vague ideas or hopes, fears I held. Seeing how to deal with these. I feel more settled and confident of dealing with the future. Not so fearful. More settled and open (woman with cancer).

Taken together, these feelings of control, support, insight and relief which clients described—in relation to a range of personal issues and in a variety of ways—help to make sense of the very positive assessment of counselling expressed in the Likert scales reported above (Table 2).

When did counselling not help? The views of those who did not benefit from counselling. Not all clients, however, gave a positive assessment of

counselling. In addition to those clients who were generally positive, but nonetheless criticised specific aspects of the organisation of the service, a small number of clients were more fundamentally negative about counselling, and indicated that they felt it had been of little benefit to them. Their comments suggest the limits of a short course of counselling in meeting the varied needs of those affected by cancer.

The most common focus of criticism derives from one of the fundamental tenets of humanistic counselling—its non-directiveness. For clients who were looking for 'advice' from the 'experts', counselling was frustratingly abstract and reflective:

> I would prefer more talk from the counsellor, rather than doing all the talking myself. I already talk a lot with my friends and family and I don't feel that the counselling offered more. I felt like a parrot—just repeating things (woman with cancer).

> I was hoping for more practical advice, not an exploration of my own emotional state, which I feel I have already explored fairly thoroughly (female relative).

This was particularly the case for a service which presented itself as a specialist cancer counselling service, which could create the expectation for medical advice or instruction on how to respond to specific situations:

> Despite a reasonable familiarity with therapy, I genuinely thought that a counsellor specifically trained regarding cancer patients would have an approach (different 'pearls of wisdom'?) that would be more valuable than a 'regular' therapist (woman with cancer).

> I expected more medical advice. My counsellor provided me with the BACUP telephone number to help me with this and now I am much clearer about it. I think I misunderstood the function of the counselling service (male friend).

The limited number of sessions allowed to clients—six or eight—was another source of complaint. While many of those who felt they had benefited from counselling also wanted more sessions, some clients felt that such a short course of counselling had prevented them from benefiting at all:

> There wasn't enough time. I didn't feel able to make the changes I needed to but I think I might have if I'd had more time (female relative).

Nevertheless, not all negative evaluations were intended as criticisms of the counselling service. For some clients, their negative assessments were grounded in their recognition that the service provided by CancerBACUP was not appropriate to their specific needs:

> BACUP was not really able to help through no fault of theirs as I have a marital problem as well and I really wanted to see someone as a couple because of this problem. Cancer was and is taking second place (man with cancer).

Or to their circumstances at the time:

> It was too far for me to travel, plus I now work at nights and am on courses during the day at short notice. So I could not attend all my meetings and left my place for someone else (man with cancer).

These latter clients felt they had not gained a great deal from their recent brief contact with counselling, but still seemed to maintain confidence in counselling itself.

DISCUSSION

This paper has presented the clients' perspective on a brief course of cancer counselling: it has described the benefits which they themselves perceived they derived from it and the focus for the dissatisfaction which a minority reported. Its strength comes from the large number of clients who provided their views on the counselling service. However, the sample represents only half of those who attended counselling and were sent an evaluation form and includes a higher proportion of those who attended more counselling sessions. The quantitative findings must, therefore, be interpreted with some caution. The main aim of the study, however, was to explore clients' views of the benefits of counselling. In a qualitative analysis, which is concerned with identifying the main themes in respondents' experience, the statistical representativeness of the sample is less important than its range and diversity.

Perhaps the most striking finding of this evaluation was the very positive attitudes towards counselling which the clients expressed: the overwhelming message was that clients found counselling valuable and derived important benefits from it. This message is perhaps even more positive than assessments of the psycho-social outcomes of counselling would lead one to expect

(Watson, 1983; Fawzy *et al.*, 1995; Moorey *et al.*, 1998). The high level of perceived benefits may reflect methodological issues, such as selection bias and social desirability, or the characteristics of those who sought out counselling. All clients were self-referred and, by definition, perceived themselves to have a problem which would be helped by counselling (Burnard, 1996). They had also contacted the counselling service at the point in the 'cancer journey' when they felt ready for counselling, which has been suggested as an explanation for successful outcomes (Moynihan *et al.*, 1998). However, while these aspects of the study design may bias the results towards a positive evaluation, the substance of the clients' comments points to specific benefits and suggests that for a self-selected population, supportive counselling in a humanistic tradition is highly valued. These benefits are consistent with the aims of counselling, but are defined in very different terms from those quantitative measures which researchers have used in assessing its outcomes.

The first and fundamental benefit which clients identified was the emotional release derived from the opportunity to talk about their responses to cancer in a 'safe' environment. Similar findings have also been described by Walker *et al.* (2000), who reported that patients found expressing strong and often negative emotions without fear of upsetting family and friends was one of the most helpful aspects of counselling. The importance of emotional release for the well-being of those in distress is well recognised (Greer, 1995; Spiegel, 1995). However, *informal* sources of social support are not always seen as appropriate or adequate for providing such release. De Leeuw *et al.* (2000), for example, found a positive relationship between the social support received by cancer patients and the experience of depressive symptoms, which they suggest could be explained as the 'side-effect' of a sense of victimisation or loss of autonomy. This may be a particular risk in relation to informal sources of support, especially family and close friends, which may, in turn, explain why many people appear to be reluctant to look to those with whom they live for support. In a separate study of those who used the CancerBACUP telephone information service, callers who lived with others were *more* likely to look for emotional support from the service than those who lived alone (Boudioni *et al.*, 1999b). Similarly, in other research we have conducted, newly diagnosed cancer patients described the 'limits' to the demands they felt they could make on family and friends for emotional support (Leydon *et al.*, 2000). By contrast, the counselling service provided a context in which clients could express thoughts and feelings, which they did not want to share with those close to them, to an individual who was skilled in dealing with them. In doing so, counselling met needs for emotional support which clients viewed as important but not easily accessible. The corollary to this, however, was that those clients who found it difficult to 'open up' to their counsellor or were looking for practical or medical 'advice', felt they gained little from this type of counselling. Sollner *et al.* (1998) report similar findings: while depressed and unsupported patients in their study wanted counselling from a psychotherapist, patients who felt insufficiently informed about their disease preferred psychosocial support from their physician.

A second set of benefits which clients identified was associated with support in examining their responses (and the responses of those close to them) with a trained counsellor. This reflects the aims of the humanistic approach taken by the counsellors at CancerBACUP, and the emphasis placed on it by clients may in part be owing to a prior sympathy for such an approach, and a willingness to be self-reflective amongst those who chose that particular service. The majority of clients were young, middle class women in paid employment who are more likely to value such an approach and to have the social skills to benefit from it. Gray *et al.* (1996), for example, in discussing gender differences in self help groups, argue that women (but not men) emphasise the importance of intimacy and benefit from a focus on emotional support and friendship. By contrast, the findings of research based on unselected samples of clinic patients (Moynihan *et al.*, 1998; Shear and Maguire, 1999) or their relatives (Goldberg and Wool, 1985; Reele, 1994) suggest that this sort of supportive counselling may be less beneficial for other sectors of the population.

Some differences between cancer patients and relatives or friends of patients were identified in the emphasis placed on the benefits they derived from counselling. The twin themes of attending to their own emotional needs and attending to the needs of others were more common in (though not exclusive to) the comments of friends and relatives. This is, perhaps, not surprising, given the way illness is regarded in contemporary Western society (Parsons, 1952). While the institution-

alised 'sick role' allows patients exemption from their responsibilities, relatives and friends are expected to provide both practical and emotional support and to subordinate their needs to those of the patient. The strain arising from this can lead to high levels of distress amongst relatives and friends which can leave them unable to provide sufficient support for their suffering partners (Fallowfield, 1995; Nijboer *et al.*, 1998). Their distress, however, can be difficult to deal with. Harrison *et al.* (1995) touched on this when they reported not only high levels of psychological distress amongst key relatives of cancer patients, but also a much greater concern amongst relatives compared with patients about the patient's emotional state. They explained this in terms of difficulties relatives experience in raising emotional issues with patients and suggest this should be a further focus for research. Similarly, Harding and Higinson (2000) describe carer ambivalence to their own needs and the desire to fulfil their duty by staying with the patient as central to the experience of carers.

The two benefits associated with confronting the fear of death—accepting their diagnosis and feeling less alone—were more common in the accounts of cancer patients. This, too, is not surprising and reflects the particular concerns of patients. Spiegel (1995) argues that fears of dying and death can be better managed by patients who know there is a time and place during which such feelings can be expressed and dealt with. He also notes that anxiety about death is exacerbated by a sense of isolation. For the cancer patients in the present sample, the opportunity counselling provided both to express their fears and to share their suffering was highly valued as helping to 'divide the desolation' of the cancer experience.

On a more general level, clients perceived counselling as helping them to come to terms with cancer and its consequences and to regain a measure of control in their lives. A sense of control is well recognised as enhancing psychological well being (Brockop *et al.*, 1989). However, while psychological research has looked to defining and measuring the coping strategies that clients adopt following psychosocial interventions (Fawzy *et al.*, 1995), clients themselves take a broader view and focus on the sense of order and control in their lives which they derive from counselling.

The qualitative analysis of clients' accounts presented in this paper provides important insights for all those involved in planning, providing or evaluating cancer counselling services. It provides a unique understanding of the benefits they derive from a short course of counselling and gives a better idea of what is attracting increasing numbers of individuals to it. Counselling appears to provide a wide range of benefits to individuals who see their problems as amenable to this form of psychosocial support and seek it out. However, these benefits may not be evident from assessments using standard quantitative research instruments and the study also demonstrates the limitations of research which relies solely on such instruments. A qualitative approach can complement and enhance the findings of standard quantitative research instruments. If carried out appropriately, assessments that explore client-defined benefits, such as those described here, may provide a more sensitive way of gauging the outcomes of cancer counselling.

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Letters

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Information needs of patients with cancer

Patients are frightened and their information needs fluctuate

EDITOR—I read the paper by Leydon et al on the information needs of patients with cancer[1] and comment both as a researcher with a particular interest in the provision of patient information and as a patient who received a diagnosis of cancer last year.

In addition to faith, hope, and charity, the patients' narratives illustrate the part fear plays in preventing patients with cancer from seeking information. The quotations in the paper echo many of my own fears, which at times prevented me from seeking information: one is frightened of finding out something bad (box 2, quote 4), one is frightened of jumping to the wrong conclusions through ignorance (box 1, quote 3) or lack of specific information about one's own condition (box 2, quote 2 and quote 6), and one is frightened of being labelled a "clever dick" (box 1, quote 4). It is important to differentiate between patients who do not seek further information about their condition because they are frightened of the potential content and those who do not seek further information because they are reluctant to ask for more details, even when they do want them (box 3, quote 2). The challenge for health professionals is to distinguish when patients want more detailed information, and the onus is on them to provide it. This will help patients to extract relevant information from other sources.

The narratives also illustrate the fluctuating information requirements of individual patients during the course of their illness (box 1, quote 4; box 2, quote 2 and quote 3), and the authors justifiably recommend further research taking a longitudinal approach to explore the changing nature of patients' orientations. Again, this mirrors my own experience. I wanted as much information as possible, but nevertheless I was terrified of being told the results of my biopsy at one visit to the clinic as I was mentally unprepared (having expected to be told the following week). There was also an internet site that I was unwilling to access on one occasion but that I readily opened a few weeks later.

In developing recommendations, the government's cancer information strategy should attend to these variations over time within individuals, in addition to the variations between patients in their desire for information.

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1 Leydon GM, Moynihan C, Boulton M, Mossman J, Boudioni M, McPherson K. Cancer patients' information needs and information seeking behaviour: in depth interview study. *BMJ* 2000;320:909-13. (1 April.)

Similar study had similar findings

EDITOR—In December 1998 we undertook a similar qualitative study to the one reported by Leydon et al,[1] using in depth interviews with 24 patients who had been given a diagnosis of cancer in the preceding 12 months; we achieved remarkably similar results.

All of the patients interviewed stated that they had experienced difficulty in retaining information given to them at the consultation when the diagnosis was given. Patients in our study also felt reluctant to ask questions if doctors and nurses appeared "too busy," afraid of making further demands on their time.

It was common for patients or a close relative to contact their general practitioner 24-48 hours after receiving the diagnosis in an attempt to gain further information. Patients expected their general practitioner to be aware of their diagnosis, which was often not the case.

We now have a system in place that ensures that consultants can request that a hospital Macmillan nurse be present when the diagnosis is given. A comfortable private area is provided after consultation, and the Macmillan nurse can accompany the patient. The Macmillan nurse provides an outline of the patient's understanding and immediate management plan to the general practitioner by telephone on the same day or within 24 hours.

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1 Leydon GM, Moynihan C, Boulton M, Mossman J, Boudioni M, McPherson K. Cancer patients' information needs and information seeking behaviour: in depth interview study. *BMJ* 2000;320:909-13. (1 April.)

Patients' perspectives may vary

EDITOR—As breast cancer survivors and consumer advocates, we know only too well the trauma associated with a diagnosis of cancer. With this background we find the study by Leydon et al disturbing and disappointing on many counts.[1]

Although it is true that not all patients wish to know the nature, cause, and treatment options for their disease, there is evidence showing that virtually all patients have a deep seated need for specific information.[2,3]

The recently released Australian guidelines for psychosocial clinical practice summarise relevant research as follows.

"Women with cancer repeatedly report a desire to be well informed. Research also indicated that up to 60% prefer key information to come from a hospital doctor. Effective communication, however, involves more than the provision of information; it requires a process of individually tailored explanation, problem-solving and acknowledgment of the woman's feelings."[4]

Why is it, then, that studies such as the one by Leydon et al continue to emphasise those patients who show little explicit need for information? Why can we not accept that there are many different reactions—from people who wish to know everything to those who wish to know almost nothing?

One of the disturbing factors about the study is its consistent portrayal of the patient as the necessary initiator of the information seeking process. Implicit throughout is the assumption that unless the patient actively seeks further information, he or she must therefore not desire any added information.

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Silence in this case does not automatically equate to satisfaction with information provision but possibly with resignation to the limitations of the system and lack of knowledge of exactly what to ask.

Similarly, if "confusion" is one reason for avoiding information this is possibly a reflection on the quality of that information and the way it has been presented, rather than a patient's desire to know and understand. To parade this as "avoidance" is merely to show a complete lack of understanding of patients' needs. This same argument can be applied to many other strategies listed by the study. Such an approach interprets the interaction between doctor and patient purely from the doctor's point of view.

With the combined experiences of consumers and evidence now available, it is time to move on and together work out how best to provide information—not to continue to argue about the need.

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Authors' reply

EDITOR—Our article on patients' information seeking and information needs has provoked a broad range of reactions. Fleissig and McKenzie reiterate some of the issues raised in our paper. Fleissig summarises many of the complexities that we attempted to convey; in particular, the way information requirements fluctuate during the course of patients' experience of cancer in accordance with individuals' orientations towards faith, hope, and charity.

Lockwood and Manaszewicz point out that it is well established that patients require as much information as possible, but some patients do not feel they get enough information, and some prefer minimal information. Our study examined the strategies adopted by patients for seeking and avoiding information. We show that patients' seeking strategies fluctuate, sometimes by the minute. It is imperative that we view patients' needs as fluid, individual, and unexpected, and, even if counterintuitive, these needs should be dominant.

We agree that women have been the focus of most research regarding information needs. Our study begins to illuminate important differences between the sexes regarding information needs and seeking behaviours, "silence" being a case in point. We have interpreted silence as "avoidance" (and other strategies) only through careful contextual, theoretically informed analysis. We have also, however, reminded readers that external constraints may act as silencers in the cancer context. A desire for no information at points in the experience of the illness can reflect a positive and rational choice. Such a choice can be indicative of individual autonomy and is one of many possible decisions to be made in the face of adversity.

We reject the assertion that our approach interprets the interaction between doctor and patient purely from the doctor's point of view. We have illuminated the need for all health professionals to be sensitive to ambiguity. Only when we begin to unpack the unequivocal ambiguity surrounding patients' reasons for non-use of information can we accurately assess whether there is unmet need. We would not subscribe to normative, blanket policies regarding the provision of information. We should instead attempt to understand the complexities of patients' information seeking and non-seeking, by properly analysing the diverse experiences of consumers. It will then be time to move on and establish how best to share in the complex process of information exchange. Until then, we believe that patients' information needs and health seeking behaviours certainly merit further attention.

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Breaking down barriers for refugee doctors

Doctors can qualify in the United Kingdom

EDITOR—Adams and Borman were right to draw attention to the need for the medical profession to help refugee doctors.[1] The United Examining Board does provide a method for these doctors to qualify in the United Kingdom and to be registered with the General Medical Council. It replaced three examinations—the conjoint examination run by the Royal Colleges of Physicians of London and Surgeons of England, the Scottish triple examinations run by the three Scottish royal colleges, and the licence of the Society of Apothecaries of London. Before candidates can sit these examinations they have to undergo a period of training and assessment in a British university.

Adams and Borman say that a mechanism needs to be established to identify refugee doctors with a good chance of re-establishing their medical careers. The United Examining Board provides this identification as it has established a preliminary examination that is used by the universities to decide who might most benefit by clinical attachment in a university hospital prior to taking the qualifying examination.

This is the only examining board route for refugee medical students who have yet to qualify as doctors. The United Examining Board has certain medical schools that organise the necessary clinical training—for example, St George's Hospital Medical School in London. For more information please contact the board's office at the Society of Apothecaries.

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1 Adams K, Borman E. Helping refugee doctors. *BMJ* 2000;320:887-8. (1 April.)

Secure statutory funding is needed

EDITOR—As Adams and Borman pointed out in their editorial, settled refugee doctors face many difficulties.[1] We have seen more than 200 during the three years that we have been working with them. Their cross cultural and linguistic skills could be especially valuable in a multicultural society. We have observed both a sense of humiliation at their reliance on benefits and a fierce determination to re-enter their profession. Recent policy changes further undermine their position—for example, supermarket vouchers cannot fund access to medical libraries.[2] Our experience has identified some problems and possible solutions that may be of interest to areas receiving refugee professionals.

- No single body takes overall responsibility; a London-wide steering group including the voluntary sector, higher education, postgraduate medical education, and local authorities has proved invaluable
- Self directed learning groups for medical education and support have been very popular. The first, of three, London clubs was in east London facilitated by one of us, a general practitioner (SC). There is continuing unmet demand for these clubs
- A clinical and communication skills course has taught 20 doctors over 15 afternoons at a cost, excluding teaching staff time, of £10 000. Half the students are now working as doctors. In contrast it takes £200 000-£250 000 to train a doctor from undergraduate entry
- One day conferences have brought together isolated refugee doctors and supportive agencies
- A refugee doctors' guide has proved an invaluable information resource to refugee doctors and agencies assisting them.[3]

Notwithstanding our achievements with short term insecure charitable funding, this

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Do men with prostate or colorectal cancer seek different information and support from women with cancer?

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Summary Male cancer patients' use of a national cancer information service, their requests and key predictors of these over the period April 1996 to March 1998 are presented, in comparison with women. The most frequent requests of 411 prostate, 162 male and 217 female colorectal cancer patients were similar: site-specific information, emotional support, publications, specific therapies. Research or clinical trials ($P < 0.05$), diet and nutrition ($P < 0.001$) requests differed between men with prostate and colorectal cancers; complementary therapies ($P < 0.05$), prognosis ($P < 0.05$) requests differed between male and female colorectal cancer patients. Among prostate cancer patients, employed men aged 60+ were more likely to need emotional support than retired men aged 70 +; men < 59 years old were more likely to request publications, but less likely to enquire about specific therapies than others. Among male colorectal cancer patients, employed men were less likely to request site-specific information, but more likely to need emotional support than retired men; patients from geographical areas other than Thames were more likely to request publications; patients from manual classes were less likely to enquire about specific therapies than those from non-manual classes. The complexity of information and support seeking behaviour is demonstrated; no pattern was found among men or in comparison with women. Further research is needed to enable development of services that are appropriate to individual needs and concerns. © 2001 Cancer Research Campaign http://www.bjcancer.com

Keywords: cancer patients; men; information and support requests; colorectal cancer; prostate cancer

Cancer is diagnosed as frequently in men as in women. In England and Wales in 1994 the female to male incidence ratio, excluding non-melanoma skin cancer, was 1:1 (ONS, 2000). However, studies have demonstrated that men are low users of cancer information services, as well as other health and social support services (Slevin et al, 1988; Greenglass, 1992; Manfredi et al, 1993; Harrison et al, 1995; Boudioni et al, 1999a; Green and Pope, 1999; Williams et al, 1999). About 60% of patients contacting the National Cancer Information Service in the USA in 1993 were female (Manfredi et al, 1993). Similarly, 80% of the CancerBACUP Information Service users in its first 2 years were women (Slevin et al, 1988). More recently, Boudioni et al (1999a) found an excess of both female enquirers and female patients enquired about among the service's first time users in a 1-year period, compared with the Great Britain population and cancer incidence in women respectively (SIRs = 1.51 and 1.18).

Other research has shown that men are not 'health aware' (Kirby and Kirby, 1999), and are far more reluctant than women to monitor their health and seek professional help at an early stage (Health Education Authority, 1996). There is also a high level of 'ignorance' amongst men about male-specific cancers, such as prostate and testicular (MORI, 1999), partly because the information is not available to them (MORI, 1999). On the other hand, the utility of information and support for cancer patients, regardless of gender, has been well documented (Audit Commission, 1993; Expert Advisory Group, 1995; Fallowfield et al, 1995; National Cancer Alliance, 1996; Leydon et al, 2000), and there are no data to suggest that men benefit less than women from support and accurate, up-to-date information.

The government and the National Cancer Director have committed to equality of care and access to everyone (Expert Advisory Group, 1995; DoH, 1997; DoH, 1998; DoH, 1999; DoH, 2000a) with the patient at the heart of the health service (The Stationery Office, 2000). The health of men has been identified as a topic of special interest (DoH, 1992). The Men's Health Forum (1997) has been calling for awareness and promotion of men's health since 1994. The Everyman Campaign – launched by the Institute of Cancer Research – has been raising awareness about prostate and testicular cancer since 1997 (MORI, 1999). Although less money has been spent on men's health than on women's, the Public Health Minister has recently announced increased funding for research on prostate cancer (DoH, 2000b).

In the light of such interest, this study was designed to examine men's health behaviour with respect to their information and support-seeking patterns. It compares men with different types of cancer (prostate and colorectal), and men and women with the same type of cancer (colorectal), who used a cancer information service. Prostate and colorectal cancers are not only among the most common cancers for men nationally, but they were also the two cancers most frequently enquired about by men with cancer

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contacting the CancerBACUP Information Service over the period April 1996 to March 1998. Breast, or another female cancer, was not selected for comparison, because of the differences in illness and treatment characteristics, publicity and awareness about the specific cancer. The main aims of the study were to describe male cancer patients' use of a national cancer information service, their information and support requests, and key predictors of these requests. A better understanding of the health behaviour of men with cancer, and those with prostate and colorectal cancers, in particular, is important for the development of information and support services that are appropriate to their needs and concerns.

SUBJECTS AND METHODS

Sampling method and data collection

An Enquirer Record Form is systematically completed for every fifth enquirer to the CancerBACUP Information Service (Boudioni et al, 1999a). An extensive coding system with 64 codes is used to record requests for information and support. A maximum of six subjects of enquiry may be recorded for every enquirer. The forms are checked thoroughly and coded; they are then entered onto the database, currently Paradox, version 5.0.

Data collected from diagnosed patients between April 1996 and March 1998 were analysed for the purposes of this study. Data for each year are kept in separate database files; the files for the years April 1996 to March 1997 and April 1997 to March 1998 were merged. Since the Enquirer Record Form is updated each year, there were some changes in the coding system, especially in the 'subject of enquiry' fields. These were taken into account when merging the data.

Enquiries originating from outside the UK were excluded, thus only British data are used. The collection of data was good and there were only a few unknowns for most variables, which were classed as missing data and are reported but excluded from the analysis. Ethnic group data were collected from August 1996 only; as there was a high percentage of unknowns and over 80% of those recorded were white British, ethnicity was not included in the analysis.

Statistical analysis

The statistical software SPSS, version 9.0, was used for data merging and for all subsequent analysis. Descriptive statistics were used initially to describe the age, employment status, social class and geographic location, as NHS regions, of prostate, and male and female colorectal, cancer patients. The most frequent subjects of enquiry of these groups were studied by tabulations and chi-square tests.

Among these patients, 'site specific information', 'emotional support / narratives', 'publications' and 'specific therapies' were the subjects or groups of subjects most frequently enquired about. The subgroups of prostate, and male and female colorectal cancer patients, enquiring about each of the four subjects were compared with all prostate, male or female colorectal cancer patients, regardless of subject of enquiry, using the Observed / Expected and Standardised Enquiry Ratio method (SER).

Logistic regression analyses were conducted initially for all patients to examine if gender, primary site or interactions were predictors of the four main subjects examined. Initial logistic regressions were also conducted for colorectal cancers to examine the effect of gender.

Logistic regression analyses were then conducted for prostate, and male and female colorectal cancer patients, to predict the presence or absence of the above four most frequent subjects or groups of subjects based on the socio-demographic variables: age, employment status, social class and geographic location. Wales was excluded from colorectal cancer analysis because of the very small number of enquiries.

The logistic regression method used for male cancer patients was backward elimination with the Likelihood-Ratio criterion. Interaction terms when a relation was suspected were used (Altman, 1997). The significance level of 0.10 for removal was used with a chosen cut off level of $P = 0.05$ for the score statistic. Significance was assessed from the reduction in the goodness of fit of the model. For female colorectal cancer patients, the significant predictors for male colorectal cancer patients were fitted, adjusted for age, into a simple enter logistic regression model. The significance of the Log Likelihood Ratio statistics, Odds Ratios and their 95% Confidence Intervals are presented.

RESULTS

Between April 1996 and March 1998, 83 440 enquiries were answered. Of these, 14 100 (16.9%) enquiries were from health professionals, students, the 'worried well' and others. The majority of enquirers represented diagnosed patients (29 370, 35.2%) and relatives and friends of patients (39 970, 47.9%).

Data on 5874 diagnosed patients were collected (one in five sample); data for 5558 diagnosed patients were entered onto the database; data for 316 patients were not entered because they were incomplete. The gender was unknown for 5 patients; of the rest, 4249 were women and 1304 were men. The female to male ratio was 3.23:1.

The two commonest cancers enquired about by male patients were prostate (411, 31.5%) and colorectal (162, 12.4%); these patients together with female colorectal cancer patients (217, 5.1% of all female cancer patients) comprised the study sample. Other main cancer sites enquired about by men included Non-Hodgkin's lymphoma (95, 7.3%) and lung (89, 6.8%). In contrast, the other main cancers enquired about by women were breast (2,502, 58.9%), ovary (265, 6.2%) and Non-Hodgkin's lymphoma (128, 3.0%).

Socio-demographic characteristics of prostate and colorectal cancer patients (Table 1)

The majority of prostate cancer patients were aged 60 or over (84.9%) and retired (61.6%); among colorectal cancer patients 59.3% of men and 47.3% of women were in this age group and 43.3% of men and 34.4% of women were retired. In all three groups, most enquirers were in non-manual social classes and more than 30% were from the Thames region.

Subjects of enquiry of prostate and colorectal cancer patients (Table 2)

The most frequent requests from prostate, and male and female colorectal cancer patients alike were for site-specific information, emotional support and reassurance, publications, information about specific therapies and treatment side effects; their order, however, varied by site and gender.

Compared with prostate cancer patients, male colorectal cancer patients enquired significantly more frequently about

Table 1 Socio-demographic characteristics of prostate, male and female colorectal cancer patients

Socio-demographic characteristics	Prostate cancer patients		Male colorectal cancer patients		Female colorectal cancer patients	
	n = 411	%	*n* = 162	%	*n* = 217	%
Age distribution						
< 49	7	1.8	15	10.0	52	25.6
50–59 yrs	51	13.3	46	30.7	55	27.1
60–69 yrs	196	51.2	47	31.3	63	31.0
70 + yrs	129	33.7	42	28.0	33	16.3
Total	**383**	**100.0**	**150**	**100.0**	**203**	**100.0**
Missing	*28*		*12*		*14*	
Employment status						
Employed	132	35.5	80	53.7	81	41.5
Retired	229	61.6	64	43.0	67	34.4
Unemployed & Other	11	3.0	5	3.3	47	24.1
Total	**372**	**100.0**	**149**	**100.0**	**195**	**100.0**
Missing	*39*		*23*		*22*	
Social class						
I	60	16.2	18	12.1	7	3.6
II	119	32.2	51	34.2	66	33.8
III(NM)	41	11.1	22	14.8	44	22.6
III(M)	55	14.9	23	15.4	4	2.1
IV & V	21	5.7	8	5.4	17	8.7
Unclassified	74	20.0	27	18.1	57	29.2
Total	**370**	**100.0**	**149**	**100.0**	**195**	**100.0**
Missing	*41*		*13*		*22*	
Geographic distribution						
North & South Thames	135	34.6	49	31.4	78	37.7
Trent, West Midlands, Anglia & Oxford	105	26.9	42	26.9	49	23.7
North & Yorkshire, North West	62	15.9	29	18.6	37	17.9
South & West	58	14.9	21	13.5	32	15.5
Wales	17	4 4	1	0.6	5	2.4
Scotland	13	3.3	14	9.0	6	2.9
Total	**390**	**100.0**	**156**	**100.0**	**207**	**100.0**
Missing	*21*		*6*		*10*	

research or clinical trials ($P < 0.05$) and diet and nutrition ($P < 0.001$); there were also significant differences in requests about specific treatments, i.e. chemotherapy, hormonal therapy and radiotherapy ($P < 0.001$).

Among patients with colorectal cancer, men requested significantly less information about complementary therapies ($P < 0.05$) and had more concerns about prognosis ($P < 0.05$) than women. Men also requested emotional support and reassurance and information about treatment side effects less frequently than women, but these did not reach significance.

The socio-demographic characteristics of the sub-groups of prostate, and male or female colorectal cancer patients, who enquired about the four most frequent subjects, were not significantly different from all prostate, male or female colorectal cancer patients. However, more employed male colorectal cancer patients needed emotional support than expected, compared with all male colorectal cancer patients who contacted the service at this period (SER = 1.34, 95% CI: 0.97–1.81).

Predictors of the four most frequent subjects of enquiry

The initial logistic regressions, taking all patients together, regardless primary site and gender, showed that primary site was a significant predictor ($P = 0.078$) for site specific information; gender was a significant predictor ($P = 0.015$) for emotional support/narratives. Primary site was a significant predictor ($P = 0.079$) for publications when gender remained at the model.

Prostate cancer patients (Table 3)

Compared with retired prostate cancer patients aged 70 years or older, employed prostate cancer patients below 59 years old were less likely, while employed and aged 60 years or older men were more likely to request emotional support. Men less than 59 years of age were significantly more likely to ask for publications, but were less likely to enquire about specific therapies than older men.

Colorectal cancer patients (Table 4)

The initial regressions for both male and female colorectal cancer patients showed that the interaction of gender with employment status was very significant ($P = 0.000$) for predicting emotional support/narratives. The interaction of gender with geographic location had an overall effect ($P = 0.137$) to publication requests. The interaction of gender with social class had an overall effect ($P = 0.159$) to specific therapies group.

The above results become more significant when we perform the analyses for males and females separately. Employed men with colorectal cancer were less likely to enquire about site-specific information, but were more likely to request emotional support than retired men. Patients from all other geographical areas were

Table 2 Frequent subjects of enquiry from prostate, male and female colorectal cancer patients

The most frequent subjects of enquiry	Prostate cancer patients		Male colorectal cancer patients		Female colorectal cancer patients		Prostate patients versus male colorectal Significance*	Male colorectal versus female colorectal Significance*
	n = 411	(%)	n = 162	(%)	n = 217	(%)		
Site specific information[1]	**140**	**(34.1)**	**43**	**(26.5)**	**64**	**(29.5)**		
Emotional support / narratives[2]	**154**	**(37.5)**	**66**	**(40.7)**	**104**	**(47.9)**		
Emotional support and reassurance	137	(33.3)	57	(35.2)	96	(44.2)		
Narratives and catharsis	17	(4.1)	9	(5.6)	8	(3.7)		
Publications / booklist[3]	**133**	**(32.4)**	**65**	**(40.1)**	**76**	**(35.0)**		
Specific therapy enquiries group[4]	**196**	**(47.7)**	**80**	**(49.4)**	**104**	**(47.9)**		
Chemotherapy	11	(2.7)	55	(34.0)	72	(33.2)	$P < 0.001$	
Complementary or alternative therapies	5	(1.2)	4	(2.5)	16	(7.4)		$P < 0.05$
Hormonal therapy	125	(30.4)	0		0		$P < 0.001$	
Radiotherapy	123	(29.9)	13	(8.0)	16	(7.4)	$P < 0.001$	
Surgery	69	(16.8)	24	(14.8)	34	(15.7)		
Treatment enquiries								
General treatment enquiry	39	(9.5)	10	(6.2)	5	(2.3)		
Treatment side effects	89	(21.7)	34	(21.0)	60	(27.6)		
Research or clinical trials	15	(3.6)	14	(8.6)	11	(5.1)	$P < 0.05$	
Treatment centres or doctors	19	(4.6)	7	(4.3)	11	(5.1)		
Other medical enquiries								
Clarification of information	65	(15.8)	21	(13.0)	34	(15.7)		
Diet and nutrition	11	(2.7)	15	(9.3)	35	(16.1)	$P < 0.001$	
Prognosis	37	(9.0)	19	(11.7)	10	(4.6)		$P < 0.05$
Recurrence	30	(7.3)	11	(6.8)	16	(7.4)		
Symptom control	31	(7 5)	10	(6.2)	17	(7.8)		
Other support								
Health professional communications	47	(11.4)	16	(9.9)	23	(10.6)		
Sexuality and sexual problems	21	(5.1)	3	(1.9)	1	(0.5)		

Enquirers could ask about a number of different issues. The nurses could code up to 6 subjects of enquiry for every user. Only the most frequent subjects enquired are presented. Numbers do not add up to the total number of enquirers. [1] 'Site specific information' related to queries for information about a particular cancer, e.g. questions like 'what is prostate cancer?' 'how does it develop?'. [2]Enquiries that required emotional support and reassurance, e.g. queries like 'how can I cope?', or related to narratives or catharsis, e.g. enquirers who wanted to talk and mainly unload themselves, were grouped togetner to form 'Emotional support/narratives'. [3]'Publications' represented any requests for Cancer BACUP booklets, fact sheets and booklists. [4]Queries about at least one specific cancer treatment (Chemotherapy, complementary or alternative therapies, hormonal therapy, immunotherapy, radiotherapy, surgery and any other cancer treatment), e.g. 'what does chemotherapy involve', were grouped together to form 'Specific therapy enquiries'. *The Pearson and Likelihood ratio Chi-squares for independence have been calculated with Yate's correction. 2-sided Exact Significance is recorded, when $P = < 0.05$.

more likely to request publications than those from Thames. Patients in manual classes were less likely to enquire about specific therapies than those in non-manual classes.

Like their male counterparts, employed women were more likely to request emotional support than retired women, and women from most other regions were more likely to request publications than those from Thames. However, in contrast to men, the most significant predictor about site-specific information enquiries was geographic location; women from Trent, West Midlands, Anglia and Oxford were less likely to enquire about site-specific information than women from Thames (odds ratio: 0.36, 95% CI: 0.15–0.88).

DISCUSSION

The sample of patients used in this study is representative of those patients contacting the service, but it is not representative of all cancer patients. Other common cancer sites, e.g. lung and Non-Hodgkin's lymphoma, have not been examined because of small sample numbers. Despite the number of people using the CancerBACUP Information Service, the small numbers of patients examined led to wide confidence intervals, may have resulted in a small number of significant variables, reduced significance levels (Altman et al, 2000) and reduced power of the goodness of fit test (Garson, 2000).

A previous analysis of first time users – patients, relatives and friends – of the information service between April 1995 and March 1996 revealed that, compared with the incidence of these cancers, there were more enquiries about prostate cancer (SIR: 1.15) and fewer enquiries about colorectal cancer (SIR for males: 0.89, SIR for females: 0.49) than expected (Boudioni et al, 1999a). The median ages of patients enquired about and the enquiry rates of unemployed and manual classes were lower than expected; enquiry rates from South and Central England were higher than expected (Boudioni et al, 1999a). The present analysis of patients using the service during the 2 following years, shows similar distributions of socio-demographic characteristics (Table 1), though enquiries from relatives and friends were excluded and a different methodology was used.

This study demonstrates that there are both similarities and differences in the information and support requests between men with different types of cancer (prostate and colorectal), and between men and women with the same type of cancer (colorectal). Interestingly, similar information was requested most frequently from all those patients (Table 2), perhaps reflecting common domains of information and support needs. The National

Table 3 Prostate cancer patients – predictors of the four most frequent subjects of enquiry ($n = 411$, Logistic regressions based on 353 cases with complete data)

Commonest subjects Significant predictors		Adjusted odds ratio	95% CI	P value**
Site specific information* **	$n = 140$			
Social class				
Non-Manual (reference category)	82	1.00		0.167
Manual	25	0.71	(0.40 to 1.26)	
Unclassified	21	0.59	(0.32 to 1.09)	
Emotional support / narratives	$n = 154$			
Age of patient and employment status*				
< 59 and employed	10	0.46	(0.20 to 1.04)	
60–69 and employed	35	1.89	(0.98 to 3.63)	
70 + and employed	13	1.84	(0.74 to 4.55)	
60–69 and retired	40	0.67	(0.38 to 1.18)	
70 + and retired (reference category)	40	1.00		0.001
Publications	$n = 133$			
Age of patient				
< 59	27	2.14	(1.09 to 4.17)	
60–69	55	0.88	(0.53 to 1.46)	
70 + (reference category)	40	1.00		0.021
Specific therapy enquiries	$n = 196$			
Age of patient				
< 59	20	0.49	(0.25 to 0.96)	
60–69	100	1.01	(0.64 to 1.61)	
70 + (reference category)	64	1.00		0.062

The variables entered into the logistic regression model were patient's age, employment status, social class and geographic location. The final model produced by backward elimination with the Likelihood-Ratio Criterion. *'< 59 and retired' category has been excluded because there were not any prostate cancer patients enquiring about emotional support/narratives in this category. **Significance of

Cancer Alliance study (1996) also reported that most men were as keen to obtain adequate information about their condition and treatment as women.

Among men, the significant differences in the rates of their enquiries about treatments and research or clinical trials may reflect the different treatments used for prostate and colorectal cancers and the research activities around them. Similarly, the treatment morbidity of colorectal cancer patients, including diarrhoea and constipation, may account for their increased need for diet and nutrition information.

Some of the differences between men and women reflect common gender stereotypes. Women's more frequent use of information services (Greenglass, 1992; Manfredi et al, 1993; Boudioni et al, 1999a; Green and Pope, 1999; Williams et al, 1999) may indicate a willingness to 'explore' alternative avenues of enquiry; they may be more open to non-conventional treatment, such as complementary therapies. Men are more interested in practical issues (Moynihan, 1998), which may explain their increased need for prognostic information. Though the occurrence of distress is similar for men and women (Fuhrer et al, 1999) women talk about their problems more openly (Harrison et al, 1995). Female colorectal cancer patients, in particular, have been found to report more emotional distress than males (Northouse et al, 2000). These findings are reflected by women in this study more frequently requesting emotional support.

This study has also identified key factors which are predictive of requests for information and support in relation to particular subjects (Tables 3 and 4). Perhaps most striking is the relationship between employment status and requests for emotional support from all patients (Tables 3 and 4). These findings highlight the impact, in Western society, of employment on the emotional needs of cancer patients (with the possible exception of younger men with prostate cancer) (Moynihan, 1996, 1998), regardless of gender, and lend support to the 'job model', rather than to the 'gender model' (Emslie et al, 1999). This is supported by the gender segregation of the labour market (Hunt and Annandale, 1999) reflected in our sample (Table 1). For men with cancer, in particular, the loss of a job can have devastating effects, both financially and psychologically (Kirby and Kirby, 1999), and the desire to get well and 'return to normal' may be expressed in terms of a desire to return to work (Seidler, 1989, 1998).

Among prostate cancer patients, age was a determinant of the kind of information or support sought (Table 3). Older men have been reported as more likely to feel 'helpless and hopeless' than younger men (Akechi et al, 1998), and may therefore need more emotional support. Older men are likely to be aware of prostate cancer (MORI, 1999), although few feel that sufficient information has been directed specifically to them (Health Education Authority, 1996). This may explain why they were less likely than younger men to request general information such as publications, but more likely to request specific therapies' information. Younger men may want to hide behind a 'brave façade' (Moynihan, 1998) and asking for written information may be easier than requesting emotional support or even information on specific therapies.

The importance of area of residence in shaping requests for publications amongst both male and female colorectal cancer patients (Table 4) may reflect regional differences in services, inequalities in NHS resource allocation or inaccessibility of health care services (Hart, 1997; The Stationery Office, 1998).

The observation that people from lower social classes make less effective use of health services (Office of Population, 1990) has

Table 4 Colorectal cancer patients – predictors of the four most frequent subjects of enquiry from males – Comparison with females

Male patients $n = 162$, Logistic regressions based on 142 cases with complete data				Female patients $n = 217$, Logistic regressions based on 187 cases with complete data			
Commonest subjects **Significant predictors**	**Adjusted odds ratio**	**95% CI odds ratio**	***P* value***	**Commonest subjects**	**Adjusted**	**95% CI**	***P* value***
Site specific information	**$n = 43$**			**Site specific information**	**$n = 64$**		
Employment status				Employment status			
Employed (reference category)	16	1.00	0.071	Employed (reference category)	24	1.00	0.868
Retired and other	22	2.02 (0.94 to 4.35)		Retired	24	1.14 (0.48 to 2.68)	
				Unemployed and other	13	0.89 (0.40 to 2.00)	
Emotional support / narratives	**$n = 66$**			**Emotional support / narratives**	**$n = 104$**		
Employment status				Employment status			
Employed (reference category)	43	1.00	0.000	Employed (reference category)	43	1.00	0.046
Retired and other	17	0.26 (0.12 to 0.53)		Retired	23	0.44 (0.19 to 1.01)	
				Unemployed and Other	27	1.26 (0.60 to 2.63)	
Publications	**$n = 65$**			**Publications****	**$n = 76$**		
NHS Health Authority				NHS Health Authority			
N & S Thames (reference category)	16	1.00	0.071	N & S Thames (reference category)	23	1.00	0.042
Trent, West Midlands, Anglia & Oxford	20	2.70 (1.06 to 6.87)		Trent, West Midlands, Anglia & Oxford	14	0.98 (0.43 to 2.24)	
North and Yorkshire, North West	12	1.88 (0.66 to 5.33)		North and Yorkshire, North West	12	1.26 (0.51 to 3.11)	
South and West	8	2.18 (0.70 to 6.89)		South and West	17	2.94 (1.21 to 7.19)	
Scotland	6	5.40 (1.49 to 19.59)		Scotland	4	5.71 (0.96 to 33.86)	
Specific therapy enquiries	**$n = 80$**			**Specific therapy enquiries*****	**$n = 104$**		
Social class				Social class			
Non-manual (reference category)	51	1.00	0.071	Non-manual (reference category)	55	1.00	0.519
Manual	10	0.38 (0.16 to 0.90)		Manual	8	0.71 (0.27 to 1.84)	
Unclassified	13	0.96 (0.37 to 2.44)		Unclassified	31	1.27 (0.67 to 2.43)	

Male patients: The variables entered into the logistic regression model for enquiries from male patients were patient's age, employment status, social class and geographic location. Wales were excluded from the logistic regression analysis for colorectal cancer. The final model produced by backward elimination with the Likelihood-Ratio Criterion. *Significance of Log Likelihood Ratio statistic, if term removed.

Female patients: For comparison, only the significant predictors for males were fitted into a simple enter logistic regression model for females, adjusted for age. The results are presented. *Significance of Log Likelihood Ratio statistic, if term removed. **This variable was also the last variable to remain when a multivariate backward logistic regression model was fitted. ***This variable was also the last variable removed from the model when a multivariate backward logistic regression model was fitted.

also been noted in this study. Again, this may reflect unequal access to information services (Manfredi et al, 1993; Harris, 1998). The lower rate of enquiry for specific treatments from male colorectal cancer patients in manual classes (Table 4) may signify a mismatch of informational needs and/or ways that information is communicated (Wynne, 1992). There may be a disinclination among certain groups to become involved with particular aspects of information (Wynne, 1992), and in this case cancer management (Van Der Mollen, 1999; Leydon et al, 2000).

In summary, this study has demonstrated the complexity that underlies the information and support seeking behaviour of male cancer patients. No single pattern of information or support seeking was found among all male patients, nor were men's requests consistently different from women's requests. No single factor was found to predict the most frequent requests; on the contrary various factors affected the requests and there were both similarities and differences by site and gender. Further research will be needed to enable a better understanding of:

- How age affects prostate cancer patients' needs for information and support.
- Colorectal cancer patients' use of health services.
- Other cancer patients and family/carers' use of health services.
- Employment issues and the effect of cancer on employment and practical/financial issues.
- Inequalities in accessibility of services and delivery of information from manual classes and people from specific regions.

The further development of information and support services for men will need to take cognisance of their overall poor take-up of existing services, different take up by men with different illness and socio-demographic characteristics (Boudioni et al, 1999a, 1999b) and of other factors that may shape the specific needs of the individual. In another study, we found, for example, that more men living alone contacted the service than those in the general population (Boudioni et al, 1999b). The use of services and some information and support requests may be shaped by the cancer site's incidence and morbidity, which deserve special consideration, as in some cases demand may surpass capacity, while in others demand is low. Delivery and development of services should be flexible and respond to requests across a wide range of subjects in a way that is sensitive to the specific needs of the individual.

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Conflict of interest

CancerBACUP provides information and support to those affected by cancer.

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Quantitative and qualitative methods in UK health research: then, now and . . . ?

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Quantitative and qualitative methods in UK health research: then, now and . . . ?

This paper examines the current status of qualitative and quantitative research in the context of UK (public) health research in cancer. It is proposed that barren competition between qualitative and quantitative methods is inevitable, but that effective synergy between them continues to be essential to research excellence. The perceived methodological utility, with respect to understanding residual uncertainties, can account for the status accorded various research techniques and these will help to explain shifts witnessed in recent years and contribute towards an understanding of what can be realistically expected in terms of future progress. It is argued that the methodological debate, though familiar to many, is worthy of rearticulation in the context of cancer research where the psychosocial aspects of living with a cancer and the related complexity of providing appropriate cancer care are being addressed across Europe, as evidenced in recent directions in policy and research.

Keywords: cancer, research paradigms, research methods.

INTRODUCTION

This paper examines the current status of qualitative and quantitative research in the context of UK (public) health research, with special reference to cancer. It is proposed that (i) barren competition between qualitative and quantitative methods is inevitable, but that (ii) effective synergy between them continues to be essential to research excellence.

Some might feel familiar with this debate. Many, however, are not familiar with or, importantly, convinced by and actively encouraging the dissolution of false dichotomies and equalizing of the two (false) methodological sides. Hence the need to rearticulate this debate. This is particularly important in the context of cancer, as an understanding of the psychosocial aspects of living with a cancer and the related complexity of providing appropriate and timely cancer care is increasingly being developed across Europe, as evidenced in policy moves and new research directions.

This paper takes research into cancer as its key focus, but the debate applies to most research cultures and illness domains. Cancer is but one dominant part of the public health 'deficit' that is characterized by long latency or induction times, aetiologies that are complex and multistage and treatments that are characterized by uncertainty and are often ineffective, invasive and/or risky. All of the aforementioned factors are common to many chronic (and acute) diseases, but cancer does distinguish itself particularly for the special fears it presents, and possibly also for its essential inevitability. Nonetheless, we are clearly always on the brink of a cancer 'break-

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through', in either treatment or causation, and almost everything diffuse and unseen seems to pose particular threats. This debate resonates strongly in the current context of cancer research as increasing numbers of multidisciplinary research teams are choosing to tackle the psycho*social* aspects of cancer in their attempts to enhance our understanding of the total cancer experience. At this time, a sound understanding of the ongoing qualitative and quantitative debate and the related application of appropriate methodologies are, it is argued, the *sine qua non* to good research. To have a proper understanding of the current debate, the origins of these methodological divisions must be understood in the broader landscape of (public) health research.

ORIGINS

The role of medicine, as discussed originally by McKeown (197), is a topic that provides a constant source of debate and discussion. Given the dramatic developments in effective medical care, not least in cancer, the debate itself has withered somewhat, but it is, nonetheless, an increasingly pertinent question. Getting to grips with 'what matters for people's health?' is at the core of the public health research agenda, and arguably it remains largely unanswered. Providing the answers is contingent on the appropriate questions being asked at the right times but also, and importantly, the adoption of a greater methodological flexibility than is currently the case.

Unfortunately, however, this is much easier said than done. Simplistic notions in health research about the distinction between qualitative and quantitative methodologies still exist, sometimes opaquely and on other occasions quite obviously so. Each is unhelpfully characterized as in some sort of competition with the other. This distinction has a long history and has mainly arisen, put simply, as a consequence of the evidence-based movement in clinical medicine and the search for evidence that can be reliably generalized to classes of individuals with illness. (Evidenced-based medicine has only recently become labelled as 'EBM', which belies the lengthy time frame of its actual gestation; Sackett & Rosenberg 1995.) For far too long, personal clinical expertise and experience, on top of didactic teaching, was the major arbiter of good medicine. With the increasing use of the recording processes permitted by the techniques of epidemiology and vital statistics (Morris 1957), it became clear that the divergent medical and surgical practices that were observed either could not all be sensible or that such treatments did not make any differences to outcome. Clearly, the latter proposition was less acceptable, and ultimately 'objective' measurements that related to outcomes had to be 'properly' compared.

Clear evidence for systematic practice variation (Bunker 1970; McPherson *et al.* 1982) that could not be explained by differences in medical need raised obvious questions of appropriateness that could not be ignored. Random allocation, enabling like to be compared with like, inevitably led to the wider acceptance of systematic assessment. Increasingly quantitative and reproducible indices of outcomes were incorporated to understand better the effect(s) that could plausibly be attributed to different treatments. The main issue had to do with encouraging an acceptable method of simple evaluation to enable valid comparisons to be made. The quality of measurement itself was initially of much lower importance, so long as its meaning was unambiguous and not subject to obvious bias.

This important process took the whole of the last half of the twentieth century and represented a 'scientific revolution' in the study of health and health care, with a strong move towards a hypothetico-deductive approach. This powerful influence has clearly changed medical practice for the better. The rapid decline in mortality from breast cancer, notwithstanding an unequivocal increase in incidence, is a prime example of this effect (Peto *et al.* 2000), i.e. as long as the main biological and positivist roots to the process, which are essential to the argument, are acceptable as (nearly) a complete explanation of the issue being investigated. But the process was essentially a transfer from a more qualitative method of assessment, invoking both theory and experience, to quantitative ones. As the logic was thought to be impeccable and the acceptance of the basic premises were so consistent with where clinical medicine wanted to be, a certain degree of widespread and uncritical acceptance was inevitable.

The intrinsic logic of counting hard end-points and using randomization was, nonetheless, only just powerful enough to persuade more intuitive clinicians that there was some sense to it. But all the time the traditional forces in medicine were dominant and, notwithstanding the power of the methodological argument and the dominant 'scientific' milieu, it was widely felt that any deviation from the core components (hard end-points and randomization) would run the serious risk of threatening the whole transformation. This was a very real threat when, variously, concerns such as the ethics of randomization under uncertainty and the role of personal evidence, so strongly confounded with reputation, remained dominant. Most individual clinicians still had, often against their better judgement, to accept that the average patient had any serious bearing on their practice, which was, after all, concerned with unique individuals.

Thus it did come to pass that statisticians and their acolytes in clinical medicine heavily disparaged notions that 'just' observing groups of people with salient characteristics could provide useful information. Indeed, it was very likely to be misleadingly biased. The whole of observational epidemiology was premised on notions of biased interpretation and the accepted means of minimizing such bias. It thus relied on strong aspirations of objective quantification and being representative, and hence generalizable.

Failing to understand properly the causes of the kind of bias that threatens generalization was a key difficulty, and people could cite stark examples of precisely why, 'unexplained' practice variation being a clear example. Increasingly, during the 1950s and 1960s, 'best' past practice, ill supported by 'hard' evidence, was, by these means, often demonstrated as inferior to alternatives. In addition, observational comparisons of groups of subjects who may well have systematically and intrinsically different prognoses were common experiences. Thus, subconsciously almost, the 'qualitative' baby (because it was still a baby in health research) went with the bath water of clinical paternalism and 'pseudo' science. Herein lies the root of the current problem.

To some degree, however, quantitative methods, as a novel idea, had run their course in that they were established as essentially the only way to reliably discern attributable biological effect and anything else was judged to be inadequate. Now, of course, it is clear to most who are engaged in the business of public health research that this methodological distinction or conceptualization has flaws, not least because it represented an oversimplification of many of the research issues to hand. For a start, 'biology' is clearly more complex than straight aggregate effects (the 'main effect' has taken on a meaning that bestows more than it means) and it is often seen to be less important than many upstream exogenous determinants of health, which now represent major health issues.

Consequentially, health researchers have entered a new era of 'discovery' of finally having to discern what each approach to the study of health can do, and, importantly, what each cannot. However, quite alarmingly, to concede that quantitative methods are not omnipotent still appears quite difficult in the context just described, but for so many reasons they are not.

The locus of this discussion rests on a disciplinary cusp in a multidisciplinary enterprise. In times past, broadly speaking, it was clinicians and statisticians and now it is essentially epidemiologists and social scientists competing for funds and reputation in the process of understanding health. There can be no overwhelming (and hence irresistible) logic to decide the futile division between qualitative and quantitative methods so cleanly. But matters are not helped by both umbrella disciplines being intrinsically marginal to what really 'matters', clinical medicine, giving succour to endless possibilities for barren contest.

The distinction rests on theoretical cultures, the central planks of which are different. Just as before a culture and professional reputation can tend to overtake the real discussion of how best to understand health and as this kind of context only obscures the real issues, we have somehow to just live with it. Conscious resistance of any kind of disciplinary imperialism must be asserted, for it is a waste of time, just as most clinical paternalism is. But as Popper (1945) pointed out, (methodological) certainties can lead to authoritarianism, and it is precisely this of which health researchers need to be continuously wary.

The baggage that goes with this entire discussion and the present and seemingly relentless dichotomization of qualitative and quantitative approaches to the study of health can be characterized by notions of (i) being 'unrepresentative' and therefore (ii) 'unscientific'. On the flip side are notions of oversimplifications associated with the greater focus on 'biased' and 'meaningless' quantification and quick, researcher-defined measurements of the phenomenon under study. The potency of the debate about therapeutic evidence essentially was able to characterize clinical paternalists as unscientific, as their patients were not representative of any coherent group and because the measure they were themselves using were often subject to measurement error and bias. Attempts to deal with this have, it is argued, to leave as little as possible to anything that might be perceived (by statisticians mainly) as subjectivity (or relatedly chance). But such arguments carry straight across the methodological divide (or more precisely the spectrum), with a different texture, but no loss of validity (Mays & Pope 1995).

BAGGAGE

One major difficulty with this debate is that the context within which it is situated acts as a constraining factor. The discussion still takes place largely in a clinical medicine setting, although health itself is the legitimate concern of public health. However, the placement of public health (almost universally) makes it difficult for the discussion to properly play itself out. Sadly, organized public health is often protected by (and for) a medical 'elite' who have themselves only recently grappled 'successfully' with the evidence-based agenda, often well behind their clinical colleagues and still unable, it seems, to have

much influence on even that agenda (McPherson & Fox 1997). If public health medicine could identify solidly with a tradition that was clearly concerned with the dispassionate understanding of health, then such discussions as these would be much less relevant.

The argument is perforce played out in public health essentially between some key disciplines: sociology (but also anthropology and history among others), statistics (but also economics among others) and public health medicine (the so-called lead discipline). Unfortunately, all of these are seen as essentially ancillary to clinical medicine, because of the peculiar role of public health medicine with respect to clinical medicine (Brandt & Gardner 2000). That is, as public health medicine is intrinsically not clinical, public health must always play a subordinate role in most clinical training and careers. (Of course Ryle (1942) has argued that public health (or social medicine) should therefore dominate clinical practice with considerable force, but that was subsequently bypassed by the potency of understanding cells, genes, pharmacology and physiology, another macro *versus* micro kind of argument.) Consequently, whatever methods are used somehow have to accommodate, bypass or override this structure. In academia, of course, these methodological hierarchies matter much less, but they do still matter.

What must be accepted more readily, however, is that there are many areas of health research (one even has to hesitate, for fear of inadvertent marginalization, before referring to it as public health research, which it is) that can only be effectively investigated using qualitative methods. Many phenomena are not quantifiable and, even when they are, it has to be accepted (more widely) that qualitative approaches can lead to novel and important insights. Qualitative methods are still too often viewed as the poor relation of quantitative approaches. Indeed, one has only to review the published literature in the world of psycho-oncology in the last year to see that such bias still exists. Basic issues such as rigour and validity are held to be overlooked by qualitative researchers. These false divisions belie the utility of qualitative methods in the cancer context and, importantly, the similarities between good qualitative and quantitative research.

It can in fact be more fruitful to consider the similarities between qualitative and quantitative enterprises, rather than falsely highlighting the differences. For example, Silverman (2001) warned us of the unthinking use of the term 'positivism' because it is difficult to define, but also because most quantitative researchers 'would argue that they do not aim to produce a science of laws (like physics) but simply aim to produce a set of cumulative generalizations based on the critical sifting of data. He goes on to state '. . . at this level, many of the apparent differences between quantitative and qualitative research should disappear' (ibid: 29). That is, we all seek to detect patterns in data based on critical analysis of the data corpus. This similarity is unhelpfully underplayed all too often, but clearly addresses the utility question directly.

Although the, possibly illusory, positivist scientific dominance of medicine is clearly beneficial to our understanding of aggregate effects (at least of biological processes) by its routine use, so new and more complex, residual uncertainties inevitably emerge. If quantitative methods are quick and increasingly conceptually simple to apply then clearly they will usually be less adequate, depending on how well all the contextual issues are properly covered by the methodology. This process of discovery, however, enlightening in aggregate will always yield new and often more complex uncertainties, because this reductionist agenda will inevitably leave too many unfilled gaps in understanding the whole. If these uncertainties, as will increasingly be the case, are less amenable to quantitative methods, the role of alternative methodologies must take their proper place. Clearly, the limits of quantitative methods for understanding health will become increasingly apparent as these residual questions assume greater importance, as they are currently doing. However, to recognize the importance of one methodology in any particular context is to say nothing about it in a different one.

Just as the methods are different to some extent they will also seek to keep each other on their toes by reminding all involved in health research of the intrinsic problems in certain applications of all methods to particular areas. Triangulation of data and results from a variety of methods requires skills not associated with any particular doctrine; this is something that requires caution. All data are context bound or tied. Simply adding results together to navigate 'truth' value is an oversimplification of how best to mix methods or adopt an eclectic methodology.

DISCOVERY

It remains the case that quantitative methodology is the core of the evidence-based paradigm and the essential ingredient for meta-analysis and overviews, all of which are certainly dominant in the medical culture. Obviously, straight transfer from randomized to observational data in meta-analyses should be, but often is not, treated with considerable caution. Unfortunately, for some cancer research(ers), the EBM agenda has an illegitimate imperialism all of its own, which is certainly to be discouraged. Inevitably, in line with this pre-eminence, qualitative

Table 1. Common conceptions of qualitative and quantitative research

Qualitative	Quantitative
Soft	Hard
Flexible	Fixed
Political	Value-free
Case study	Survey
Speculative	Hypothesis testing
Grounded	Abstract

Source: Silverman (2001).

methodologists still perceive (and arguably experience) major barriers to acceptability.

Silverman (2001) recently highlighted the common ways in which qualitative and quantitative studies are still conceptualized; one usually referring to 'good' standard research and the other to 'bad' (Table 1).

What often are portrayed as weaknesses of qualitative methods must increasingly be viewed as strengths. For example, qualitative researchers (broadly speaking) tend to be more self-critical or, put more positively, self-reflective. This, in large part, can be accounted for by their realization that data can never be value-free and that data collection will raise expectations, perhaps because they interact more with people in the process of data collection and feel more of a duty to them (Weber 1946). Qualitative research permits a consideration of the role of the researcher in the research enterprise. Reflexivity is variously defined in the world of qualitative research, but all definitions rest on the fact that the researcher is not a neutral research instrument or gatherer of 'facts', but rather is reflexively tied to the conduct and outcome of the research. This epistemological standpoint is critically important when dealing with people who, when interviewed or 'observed', for example, are at a particularly difficult and vulnerable stage in their life course. Somehow, to not recognize the importance of reflexivity or to not recognize the importance of individual patient voices in this whole research endeavour represents a serious omission.

A prime example is the growth of interest in communications research in the cancer field, specifically work on how doctors relay diagnostic information to their patients. The by far pre-eminent and conventional approach often draws on naturally occurring materials, which is to be encouraged. However, all too often the talk of doctors and patients is straightforwardly separated and abstracted from the circumstances of their production. To describe what doctors do in interaction, without also considering the sequentially implicative work in which patients are engaged, belies the doubly contextual nature of interaction. It is context-shaped because participants rely on the immediately preceding utterance to understand what it is they have heard and to produce a relevant next utterance. It is context-renewing in that every current action paves the way for subsequent actions (Heritage 1985: 1). In short, if the concern lies with how doctors and patients communicate, then doctors' actions must surely be analysed in relation to the sequentially implicative work of patients. Paradoxically, despite the attention to patients' 'needs', the popular approach to 'communication' in quantitative work in the cancer field can belie the significance of the role of the patient. Qualitative methodologies have sought to unpack the 'art' of interaction for decades. Standardized techniques can provide for an understanding of this sequential character of communication or more straightforwardly can capture the process of communication. Counting different kinds of speech acts by doctors (such as closed and open questioning), although useful for other reasons, cannot.

Qualitative research in the cancer field is often placed low down in the hierarchy of research activity because of a problem of size: in short, for being too small and hence anecdotal. Recently, a contribution to the literature by Costain Schou & Hewison (1999) provided a compelling argument in favour of small-scale work because of the richness and depth that can accompany such work. Costain Schou & Hewison (ibid.) demonstrated the importance of qualitative work in being able to explicate precisely how the cancer experience is, in essence, experienced. What it is like to be diagnosed with cancer, what it is like to be treated and what can be done to improve quality of life in treatment were all issues that were convincingly tackled by Costain Schou & Hewison Unfortunately, their work would all too readily be dismissed in our dominant quantitative culture for one reason alone, the fact that it was based on *just* 44 interviews. This kind of rejection can only be limiting in the end to our attempts to truly understand the cancer experience. Ambiguity is very much a part of the fabric of life and personhood. Lived experience is rarely diaphanous in nature, nor is the illness experience. Consequently, to encourage a methodological world that is (superficially) straightforward runs counter to this knowledge.

In this whole methodological debate, dialectical reasoning seems to escape in favour of reductionist claims and a dichromatic framing of a (methodological and experiential) situation that is so complex that it is kaleidoscopic in nature. This pedestrian position needs to be challenged, particularly now.

We do need to understand ways of effectively enabling change for the better, where they exist. Patient-centred-

ness is taken very seriously in psycho-oncology, what is not taken so seriously, however, is the utility of qualitative methods in providing novel and insightful (not forgetting rigorous) ways of understanding the voice at the heart of patient-centredness and in placing it centre stage in current research. It is simply not enough to assert that 'mind over matter' has limits; we need to know where those limits are, and we are a long way from that. Certainly, purely quantitative approaches will not be enough to effectively pursue this agenda. Randomized trials can be seriously biased by subtle endogenous influences of preferences on treatment efficacy (McPherson & Britton 1999). We shall have to see whether such changes in research emphasis can happen, but they will require an irrefutable example of the extent of the uncertainties first. That itself might require a sea change depending on whether genuine uncertainties will dominate the research agenda. This is a classical Catch 22, but clearly such uncertainties (and an acceptance of ambiguity and the fluidity of patient experience) should. Building a reliable evidence base must precede the proper development of a coherent research agenda, not the other way round.

CONCLUSIONS

We have argued here that the discussion must first be perceived as a serious issue even in the twenty-first century and it must centre increasingly on methodological utility (as opposed to the futility of needless or meaningless distinctions) for health. It is precisely this starting point for debate that enables a constructive approach to the problematic qualitative and quantitative (so-called) dichotomy. Neither is worth encouraging for its putative intrinsic merits, only for its particular merits in the context of improving people's health, necessarily via a better understanding of health-enhancing processes, wherever they matter. Other arguments are sterile in this context (Sacket & Wennberg 1997). As Silverman (2001) has recently argued '. . . the value of a research method should properly be gauged solely in relation to what it is trying to find out' and should not be based on some empty or glossed version of what qualitative and quantitative methods mean: counting *versus* not counting. Nor should it be based on some misplaced loyalty to one approach over another. Moreover, if all qualitative research methods are defined as the opposite of the quantitative preference for counting, what it is or what it offers remains unclear. As Silverman (2001: 25), contends 'to call yourself a "qualitative" researcher settles surprisingly little. First, "qualitative research" covers a wide range of different, even conflicting, activities. Second, if the description is being used merely as some sort of negative epithet (saying what we are not, i.e. non-quantitative), then I am not clear how useful it is'.

Unless those engaged in the business of cancer research sit up and take note that this debate still holds currency today, in a very real way, and methodological pluralism is encouraged rather than merely tolerated, we cannot hope for qualitative research to ever be taken as seriously as its (falsely defined) opposite. Indeed, it will not be seen to be stand-alone research and rather sadly is destined to be coined 'exploratory' forever.

We need to continue to build a research infrastructure that symbolizes and supports what most of us already realize, i.e. all data collection techniques have a place in our tool bags and interpretative and positivist methodologies have a place in our minds when conceptualizing the important questions in cancer that are worthy of our attention in 2002 and beyond. Without a greater acceptance of this position, the challenges that face us in our current attempts to broaden our understanding of the entire patient (or person) experience will not be adequately met.

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The journey towards a cancer diagnosis: the experiences of people with cancer, their family and carers

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The journey towards a cancer diagnosis: the experiences of people with cancer, their family and carers

This small-scale study aimed to provide an insight into the time between first noticing a symptom, attending a healthcare provider and obtaining a cancer diagnosis. Previous research showed that the pre-diagnostic moments on the illness trajectory were important to people with cancer and could influence levels of satisfaction with subsequent care. This article provides an overview of the qualitative component (phase 2) of a three-pronged study that involved a workshop, a literature review and focus groups and interviews with people affected by cancer. Results highlighted some of the difficulties encountered during the complex journey towards a diagnosis of cancer. These included fear of what might be found, communication of symptoms to healthcare practitioners, the influence of family on decisions to attend a primary care practitioner and the importance of a person's gender on perceptions of health-seeking behaviour. Results presented warrant further investigation and suggest the importance of viewing the 'cancer journey' as including the journey leading up to a diagnosis of cancer.

Keywords: pre-diagnostic cancer journey, health-seeking behaviour, patient and family perspectives.

INTRODUCTION

For most cancers, survival is lower among socioeconomically disadvantaged patients in England and Wales than for the more affluent (Coleman *et al.* 1999). Poor cancer survival can be attributed to many factors, including delay in access to appropriate care (Sheridan *et al.* 1971; Wilkinson *et al.* 1979; Elwood & Moorehead 1980; Feldman *et al.* 1983; Vernon *et al.* 1985; Neale *et al.* 1986; Rossi *et al.* 1990; Porta *et al.* 1991; Richardson *et al.* 1992; Lannin *et al.* 1998; Coates 1999; Ramirez *et al.* 1999; Richards *et al.* 1999). Patients from socioeconomically disadvantaged groups also present with more advanced disease (Wilkinson *et al.* 1979; Elwood & Moorehead 1980; Vernon *et al.* 1985; Neale *et al.* 1986; Rossi *et al.* 1990; Richardson *et al.* 1992; Schrijvers *et al.* 1995a, b; Lannin *et al.* 1998; Richards *et al.* 1999). In recognition of differences between segments of the cancer population in terms of the need for and the uptake of health services, as well as in survival, Macmillan Cancer Relief commissioned this exploratory study to add to current knowledge of the journey towards a cancer diagnosis.

Recent policy has emphasized a need to reduce the cancer burden and improve the availability of services to those affected by cancer (DoH 2000). The NHS Cancer Plan acknowledged the importance of variations in both cancer risk and cancer services: '. . . there are real inequal-

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ities in this country in terms of who gets cancer and what happens to them when they do' (DoH 2000). In order to reduce such inequalities, the government has recognized the need to work with organizations like Macmillan Cancer Relief 'to extend the range and accessibility of cancer services right across the country' (DoH 2000).

This small-scale project aimed to provide an insight into the time between first noticing a symptom, attending a healthcare provider and obtaining a diagnosis. The focus arose from results of an earlier questionnaire and in-depth interview study (Leydon *et al.* 2001a), which found that the pre-diagnostic moments on the illness trajectory were important to people with cancer and could influence levels of satisfaction with subsequent care. For example, system delay and regrets about a lack of provision of systematic information or support during the early stages and minimal or no orientation to cancer possibilities during the testing process were all emergent themes.

The study reported in this article included three data collection phases: a detailed review of the published and grey literature (phase 1), a qualitative study using interviews and focus groups with patients, their family and carers affected by cancer (phase 2) and a national 1-day workshop (phase 3), to discuss preliminary results and other priorities. The workshop was attended by over 80 health practitioners, service managers, charity sector workers, government representatives and academics, all of whom were invited to discuss the preliminary results of the qualitative study. This article provides an overview of the qualitative component (phase 2). The results of the other two phases are reported separately (Leydon *et al.* 2001b).

METHODS

Fieldwork was carried out during April to September 2001. Semi-structured telephone and face-to-face interviews and focus groups were used to explore individuals' personal experiences of the cancer journey, with special reference to pre-diagnostic experiences (the time before a cancer diagnosis had been confirmed/delivered).

Approach

The interview schedule and focus group topic guide focused on the research question, but they were sufficiently flexible to permit respondents to raise issues of concern to them. An interest in patient experiences as reported in their 'own' words (albeit in the research-instigated context of interview or focus group) fuelled the design of the study.

Recruitment

People with an experience of cancer were first contacted and invited to participate through a range of UK community-based organizations [Cancer Black Care, Cancer Care Society, Cancer You Are Not Alone (CYANA) and Cancer Equality] specializing in the provision of support to those affected by cancer, and not through their National Health Service (NHS) provider. Ethics approval was forthcoming from the internal ethics committee of the London School of Hygiene and Tropical Medicine.

Potential participants were given detailed information sheets about the study, and all participants provided informed written consent, witnessed by one of the researchers. Study Information Sheets were backed up with verbal explanation of the study. Participants were informed that participation would involve discussing (possibly) painful memories or events and they were told that they could stop the interview or focus group if necessary. They were also told that the researcher would help them to seek out expert support or information if required, following their participation (no one requested this advice). Aware of the potential sensitivity of the groups accessed (ill, bereaved, carers) and the issues to be discussed, the needs of participants were prioritized.

The sample of community groups was purposively drawn in an attempt to obtain individuals from certain population groups, in particular, those known to use conventional information and support services less than others do (men, the elderly and the economically poor) (Boudioni *et al.* 1999) and have lower survival rates (Schrijvers *et al.* 1995a, b; Lannin *et al.* 1998)[1]. Because of slow recruitment, a convenience snowball approach was used for the latter half of the sample (focus groups), drawing on naturally occurring/ready assembled groups in the community groups.

To participate, individuals had to be aged 18 years or over, to be aware of their diagnosis (this was known through their participation in cancer community groups) and to have been diagnosed within the previous 2 years (to avoid a sample that was too heterogeneous in terms of time since diagnosis and to limit the related problems of recall). Carers and family were included to obtain additional insight into the journey towards diagnosis. Often,

[1]As far as possible, the final sample was drawn based on individual's socioeconomic status, with occupational status being the main criterion. This measure, although limited, represented a pragmatic approach to recruitment. Other possibly more appropriate and sophisticated indicators were not available to the research team in advance of the fieldwork. Relevant occupations were held to be those that fall into categories 5–7 of the Office for National Statistics' socioeconomic classification. These include lower technical, manual and clerical occupations and the unemployed, and those with limiting long-term illness.

those with serious illness will be accompanied along the illness path by a significant other from a very early stage for tests, procedures and consultations. Hence, there was the wish to provide the opportunity for those shared experiences and knowledge bases to be captured at interview and during the focus group sessions.

A retrospective approach was pragmatically selected in favour of a prospective approach because of time and practical methodological constraints. Nevertheless, a majority of interview studies are retrospective and produce rich insights into patient perspectives about past events.

Interviews

Interviews (17) were conducted over the telephone and face-to-face. It was acknowledged that for such personal accounts, telephone contact might limit the ability of the interviewer to build rapport with participants, but the importance of contacting individuals from a broad range of geographical regions was felt to balance this concern. In the event, using a telephone approach did not seem to compromise the quality of the data, and some participants actually stated a preference for this kind of contact.

Interviews covered patients' perceptions of the process of diagnosis, including how easily the general practitioner (GP) had detected their symptoms as suggestive of cancer, delay between presumptive diagnosis and referral for specialist opinion, and ease of communication with the GP or specialist. Interviews typically lasted 45 min, and were audiotaped, transcribed verbatim and later analysed for content using a thematic approach. The interviewer's notes were used to augment interview transcripts. A second researcher in a sample of transcripts checked the validity of themes.

Focus groups

One of the researchers led the participants in a discussion of key topics (in three groups), including their perceptions of the NHS and its ability to treat cancer, perceived barriers to accessing primary care with their symptoms, and the financial and social costs associated with being ill and having treatment. Discussions lasted an average of 90 min and were conducted in a setting familiar to the participants (all in community-based cancer charities in a deprived ward in London). A scribe took notes during each session, and audio recordings were taken for verbatim transcription. Transcripts were then analysed for thematic content by the interviewer, and themes were checked in a sample of interviews by a second researcher.

Key themes identified from both the focus groups and the telephone interviews are presented for this overview. More detailed coverage can be found in Leydon *et al.* (2001b).

RESULTS

Sample characteristics

Overall, 33 people aged 54–74 years with experience of cancer participated. Semi-structured interviews were conducted by telephone with 17 participants (five men, 12 women) (Table 1). Two men declined to participate: one felt that a telephone interview would be difficult and another did not feel comfortable talking about his illness. Three focus groups were conducted with a total of 16 participants. Focus group 1 comprised five Asian women. Focus group 2 comprised a mixed group of carers and patients (five women, two men). Focus group 3 comprised four Asian women (non-English speaking) and was conducted by an interpreter (Table 2).

Key themes

Several key pre-diagnostic factors emerged as reported influences on access to care after cancer or serious illness was suspected or once participants had begun to feel unwell or experience symptoms. Here, we discuss five of these key influences: the role of family and significant others, fear, the communication of symptoms or concerns, patient rationalizations for difficult experiences during the journey towards diagnosis and the relevance of gender to attitudes towards seeking health intervention.

Family and friends: a reason for delay and a reason for action

Perceptions of whether cancer was something 'that will happen to me' were clearly related to people's social networks, in particular participants' individual experiences of whether family or friends had had a cancer.

Some felt that significant others had enabled them to attend a general practice and to face up to their fears. Traditional caring roles that are often associated with significant others were discussed. An 'ethic of care' for others (Day 2000) was key in the accounts offered by study participants:

> Well me wife helped me more or less all the time, you know she kept saying go to the doctor and I wouldn't go to the doctor's and, at the back of me mind all the time with me dad dying of lung cancer,

Table 1. Description of interview sample

Respondent	Gender	Age (years)	Cancer	Occupation	Location	Ethnicity
1	M	45	Bowel	Postman	Cardiff	English
2	M	68	Prostate	Retired	Derbyshire	English
3	F	59	Lung	Cleaner	W. Yorkshire	English
4	M	67	Lung	Wire worker	Nottinghamshire	English
5	F	57	Leukaemia	Medical secretary	Cardiff	Welsh
6	F	62	Colon	Unemployed	Nottinghamshire	English
7	M	74	Colorectal	Retired guard	Nottinghamshire	English
8	F	55	Breast	Part-time cleaner	Birmingham	English
9	F	56	Breast	Traffic warden	Stoke Newington	Black (West Indian)
10	F	38	Breast	Factory worker	Essex	Asian Indian (Sikh)
11	F	35	Breast	Factory worker	Stratford	Asian Indian (Hindu)
12	F	37	Breast	Unemployed	Little Ilford, London	Asian Bangladeshi (Muslim)
13	F	66	Ovarian	Unemployed	Notting Hill, London	Asian Sri Lankan (Buddhist)
14	M	45	Stomach	Chef	Croydon	Asian Indian (Hindu)
15	F	57	Leukaemia	Pharmacy sales assistant	London	Asian Pakistani (Muslim)
16	F	52	Breast	Sales assistant	Middlesex	Asian Hindu
17	F	58	Lymphoma	Civil servant	Croydon	Asian Indian (Hindu)

M, male; F, female.

Table 2. Focus group composition

Focus group 1	Five women of Asian origin with breast and ovarian cancer
Focus group 2	Seven male and female patients and carers of various ethnic backgrounds, including English and West Indian
Focus group 3	Four women of Asian origin aged 30–70 years who were not English-speaking, conducted by a specialist consultant in their language. The tape was translated before transcription

> I thought, I wondered if that was what was wrong with me, because I was in pain some days and some days it wouldn't be there, and I took it to be just stomach trouble you know, indigestion or something like that. (R4: male, 67, retired wire worker, lung cancer.)

The reference to the experiences of relatives was typical of how participants (especially those with a cancer experience themselves) reacted in the face of illness. They reported an approach that involved downplaying the symptoms, while invoking the maxim 'I didn't think it would happen to me'. For others, a perceived desire to protect their family members precluded them seeking help for themselves:

> It (her husband's admission that he had major concern about his prostate which he kept from her) came at the last minute, when I was talking to him, he said I did not want you and the children to worry. (Focus group participant, female, West Indian origin, whose husband died of prostate cancer.)

Protection of this kind seemed to threaten an individual's ability to feel supported and left some feeling isolated with their concerns about a suspected illness, during the early pre-diagnostic moments.

For others, family members were the first and only point of contact about early concerns.

> Interviewer: . . . during this time did you suspect that you were seriously ill?
> R6: Yeah.
> Interviewer: OK did you express this concern to the doctor or, or did you, it was something that you just kept within you?
> R6: I just kept it to myself.
> Interviewer: Did you discuss it with anyone?
> R6: Only my daughter. (Male, 62, unemployed, colorectal cancer.)

The role of families and friends, experiences grounded in those networks and health-seeking behaviour were interwoven with fear.

Fear: a barrier to attending the doctor

There was an over-arching concern about pain and fear of death when talking about cancer, often stemming from the experiences of family and friends. Fear was an important theme in the context of when to attend a doctor. For the majority of respondents, arguably quite sensibly, there was a strong association between fear of pain or death and a cancer diagnosis.

> . . . when they diagnosed that for me I just, er, come home and I always think positive but at the back of me mind all the time I think I am definitely going to

> die, I don't know why but, I don't know if that's how other patients see it but when they mention lung cancer you fear the worst . . . Like the big C, when you mention that you, your mind, you don't function right, in fact. (R4)

Fear of cancer was strongly associated with the fear that it was a recurring disease that would never be cured. The perceived inevitability of death and references to a fear that cancer would eventually recur and 'go to the bones', even by those who received quick and successful intervention at an early stage, revealed a strong need for follow-up and support at the end of treatment. Accounts implied a need to be supported in their efforts to return to a 'life as normal' as quickly as possible, but with recognition of the impact that a cancer experience can continue to have on daily life for some time thereafter. By contrast, for some, 'positive thinking' and reports of a 'fighting spirit' provided a way of talking about their experiences at interview. These two approaches were clearly not mutually exclusive, the same respondent as above, R4, continued with a positive line below and stated:

> Well my own personal outlook on life is to get on with life, isn't it, you know and think positive all the time. (R4)

These expressions of stoicism or fear were sometimes related to participants' descriptions of communicating with health professionals during the pre-diagnostic and diagnostic period. For some, reluctance to pursue a referral was related to hesitance about being seen as too 'pushy' or in coming across as too fearful in the face of no real illness. The seemingly endemic recourse to sporting or war metaphors (see Sontag 1991; Seale 2001) – fighting or battling – in the context of cancer was yet again revealed. It highlighted a possible double bind for patients. 'Fighting' was not the panacea and this was clearly illustrated by another terminally ill man with cancer on a recently televised documentary entitled 'Death', who said, 'Some people can take a lot more than others. I am a stupid weakling. I don't mean to be though' (Channel 4 television, Tuesday 30 July 2002).

Going to the doctor: the communication of symptoms

When asked to discuss their feelings on communication with key healthcare providers during the pre-diagnostic period, participants' reports varied from no problems at all to the need for recurrent visits to the GP before being 'taken seriously'.

Difficulties in communicating the disruption caused by their symptoms sometimes prevented patients from pressing the primary care provider to refer them for further investigation, after being told that their symptoms were nothing to be worried about.

> And over eighteen months I had three what I thought as periods . . . Each time I went to my GP but I knew at my age I shouldn't be having these. (R5, female, 57, secretary, leukaemia.)

Perseverance in seeking help when faced with a problem that is not at first taken seriously also caused difficulties:

> And, um, I said that I think I've got a little problem down there, but nothing happened, more to the point I can't think what was said, but nothing else happened, and I mentioned this to this same doctor twice, definitely twice but possibly three times, but it never went any further . . . so that was some three odd years ago, possibly more . . . It was disappointing to me when I think back that, um, you know I had spoken to a doctor, that I thought I had a problem and that that didn't go forward . . . But I do know that you know I had a problem down there and I'd had patches where my private parts are. (R2: male, 68, retired, prostate cancer.)

Several patients reported misdiagnosis or delay in diagnosis and feelings of disappointment were reported in this regard. One man reportedly went to three hospitals and experienced a misdiagnosis of gallstones before being diagnosed with bowel cancer. Another man underwent tests for over 9 months before being discharged and told that nothing was wrong. He insisted on returning for repeat tests and reported thus:

> Interviewer: How are you feeling about the early days, I am asking you to cast your mind back?
> R7: Well, er, I am a bit mad about it (laughs) . . . about the diagnosis road. I went twice, the first time they said nothing was wrong but I blame the hospital for all my trouble . . . I was probably going a year before they diagnosed and discharged me, I had all the tests and they discharged me and said nothing was wrong . . . Then I insisted on going again . . . He said I'll send you back and I were there and within three weeks they knew everything.
> Interviewer: mmm.
> R7: and that's when they . . . and I can tell you the exact words of Mr/X the surgeon. He said – 'I don't know how we missed it the last time'. (Male, 74, retired guard, colorectal cancer.)

Seven out of 17 respondents (R1, R2, R4, R6, R7, R13 and R14) volunteered stories of delay. In every case, individuals who thought they had been misdiagnosed were angry about the diagnostic experience. This anger has implications for the rest of the cancer journey in terms of satisfaction and trust in the care that they receive.

Getting diagnosed: rationalizations of bad early experiences

Difficulties in getting recognized at the primary care level were often rationalized in the context of scarce resources (see also Leydon *et al.* 2000). Awareness of the queuing system and resource scarcity tempered patients' expectations. How this was addressed varied. One patient on a waiting list, who worked in a hospital herself, expressed the view that 'people are lucky if seen quickly'. However, working in the hospital provided her with local knowledge of the NHS, and resulted in shorter waits. She indicated that she 'pulled strings' to be seen quickly. Another individual waited for diagnostic tests for over 4 months. She expressed anger at waiting, but this was tempered with pragmatic realism: 'I lived in a deprived area with an overdemand for services, I would have no choice but to wait.'

During one focus group, much discussion was devoted to inadequacies of the current NHS system. Not surprisingly, there was a tendency to view private care as superior for getting quick access to a diagnosis and treatment. A rationed health service provided a rationalization of the extended waits:

> Patient 1: The government – the pressures on them, they can't do their jobs that they should.
> Patient 2: No, I think, you know, I think everybody's under pressure. They can't do their jobs properly because it – the government funding, and what have you, they can only, em, if you have a problem, they can only refer you to a hospital to have the test made and what have you. They can't force you to have a test next week. You know? I mean I've got to wait seven months to have an endoscopy, and the doctor said, he said, [name], my hands are tied. I cannot do anything.
> Male carer: Yeah – that's right.
> Patient 2: So I'm being referred, and unfortunately, it's like catch 22, you know, and I think if you're – if you're private, a private patient, there's no problem whatsoever. But if you're NHS . . . (Focus group 2 participants.)

Other concerns about the healthcare system during this same discussion included 10-min consultations in GP surgeries, too much pressure on GPs, too much paperwork for GPs and an increased need for the doctor to visit patients who are reluctant to come into surgery.

A series of reasons for problems experienced by patients in a relatively deprived London borough were offered. Some of these related to a mistrust of professional expertise at the primary care level:

> Male carer: . . . They're not trained sufficiently to diagnose you early, that's where the deaths come in. Not because of the operations, once you're in the hospital it's generally satisfactory because if your doctor doesn't turn up you'll get another one. . . . There's a great deal of difference between the quality of the doctors, the GPs, there's a great deal of difference between a number of GPs, they are not trained sufficiently or they don't care.
> Female carer 1: I think they're trying. Focus group 1 participants.)

And another interviewee stated thus:

> R1: Um, well of course I can't say. how easy it is to diagnose cancer, er, the only thing I would say that the bowel was fully blocked, um, I would have thought that something would have shown up on the scan, however, having said that, um, we all make mistakes.
> Interviewer: OK.
> R1: Um, maybe not as important as that but, er, we do make them and, um, maybe, maybe er, the people on the other end of the scanner was having a bad day, you know.
> Interviewer: I see, that's been, that's your main concern about your experience.
> R1: Yes, I would say about the . . . er, first visit, yes. The second visit I would say, well, you know maybe they didn't just didn't have the knowledge, um, to deal with the, the problem at that time. (Male, 45, postman, bowel cancer.)

Data analysis revealed possible differences in experiences and expectations. The particular type of cancer could influence individuals' journey towards diagnosis. The breast cancer patients in both focus groups and telephone interviews appeared to be generally pleased with the response of their GPs to their communication of their symptoms.

Participants, however, perceived a patient's geographical location as a major determinant of the time between referral, obtaining diagnostic tests and seeing a consultant. Strategies of coping with the various shortcomings of their boroughs were discussed. One focus group

participant residing in an inner London borough was given a 3-month waiting time to see a specialist. She switched to private care provided by her employer and was diagnosed and operated on within 8 days at a private hospital. Clearly, not everyone will have this option.

Gender: delay and social roles

Some of the factors that were accounted for as constraints to seeking care among both men and women drew on gender roles. Women, for example, identified caring for children, and household and business responsibilities as inhibiting prompt access to medical care. One woman with children reported fears about keeping her family unit together; she was a key support for her daughter, whose marriage was troubled by her own struggles with cancer. This 'ethic of care' (Day 2000) is not specific to the cancer experience, but its existence is important if early detection strategies are to accommodate the multifarious influences and constraints on people's health-seeking behaviours.

Men also highlighted being busy with work as well as family responsibilities. For one man, ill health was simply considered to be an 'occupational hazard'. A reluctance to confront death or serious illness was also shared. One participant regretfully reported leaving his symptoms for 2 years and normalizing his symptoms of breathlessness by referring to his dusty work environment:

> I were busy at work and I was enjoying life, and I just chose to shrug it off and think you know, er, all this work environment . . . dust and that, and I just never thought nothing, you know. (R4)

When asked what would improve the health service for other people, he commented thus:

> I'd let them know [other people] the dangers of things about cancer and if they feel as if there is something drastically wrong, to go straight away to the doctor. (R4)

Men's perceived reluctance to discuss health concerns with each other formed a subject of discussion:

> Women talk more together about these things, you know, than what men do . . . I never talk to [male friend] about testicular cancer, but you talk about breast cancer openly, isn't it? (Focus group 2 participant, male carer, whose wife died of ovarian cancer.)

Men explored these differences and their influence on pre-diagnostic events. They accounted for the differences by calling on traditional social (and gender-specific) roles and behaviours, such as women's more frequent visits to the doctor and their wider use of support services (Greenglass 1992; Harrison *et al.* 1995; Boudioni *et al.* 1999), and women's greater presence in the family home. Women in the group did not challenge these characterizations. Rather, they spoke about their responsibilities not just for their own health care, but also for the health of significant others – children, husbands, mothers and fathers as well as their 'breadwinning' role. These descriptions highlighted the actual similarities in the pressures on and roles of men and women – while also underscoring the perceived differences when gender was used as an explanatory concept for possible delay and difficulty.

Often the practical and financial burden of disease at an individual level is obscured or ignored, but concerns raised during the focus group related to the cost of car parking in hospital facilities, loss of income while accessing health care and the inability to manage family businesses. These concerns affect men and women and all social groups, but with varying severity and with different consequences. Of importance is that overall participants reported a philosophy of silent self-management, without utilizing the support of services around them. Whether these particular accounts represent another manifestation of 'stoicism' in the face of their adversity or reluctance or lack of knowledge of services available is unclear from this analysis.

DISCUSSION

This article has attempted to provide some insights into the early phases of the cancer journey among a broad range of people affected by cancer; some of whom were from disadvantaged (and marginalized) sectors of society. The sample is too small for the results to be definitive. Limitations relate to the composition of the study sample; men proved more difficult to recruit. In part, this gender skew was more a consequence of using community support groups (men are less likely to use such groups, creating a gender skew) than of a high level of refusal among men (only two men refused). Furthermore, the use of community groups meant that the experiences of people who are familiar and comfortable with talking about their illness experiences were elicited. By implication, therefore, the experiences of individuals who might find it difficult to participate in community groups and whose illness experiences remain relatively unknown were not accessed. Overall, the sample was too small to undertake detailed exploration by characteristics such as gender, and different perspectives based on 'group membership' such as carer vs. patient.

Notwithstanding these limitations, the study suggests several areas warranting further exploration, and the similarity with other studies permits greater confidence in the results (e.g. Moynihan 1998; Leydon *et al.* 2001a). These similarities raise two important points, which although not related to the substantive findings of the study are nonetheless worth discussing.

First, the similarities with findings in other studies might arise partly from the fact that 'hard to reach' patients were also 'harder to reach' for this study sample. In the end, we captured the experiences of a range of people, some with socio-demographic characteristics that would normally imply 'disadvantage' and others with characteristics common to groups who would not normally be classified in this way.

Second, the similarities in the themes evoked by many study participants (and between this and other studies) arguably reflect a genuine commonality of experience between those with serious illness, in this case, those with a cancer experience. The fears and concerns of those affected by cancer are not necessarily contingent upon or determined by one particular circumstance, e.g. financial hardship or cultural background. These reported experiences reflect, broadly speaking, 'human need', but undoubtedly they will sometimes be harder to fulfil (e.g. for an individual who is faced with financial hardship when compared to an individual who is not) and harder to meet (e.g. by a health professional operating in an increasingly rationed health service when compared to a health professional working in the private sector).

Individual factors (e.g. recognition of key symptoms, fear and comfort or motivation to pursue medical intervention, and protecting family members) and exogenous factors, which are mostly structural in nature (e.g. an overstretched health service and delays at the primary care level), can help to explain some of the reasons for not accessing a cancer diagnosis or for going to the doctor promptly, when faced with symptoms of illness. Some of the structural and individual barriers were clearly interwoven with the material status of participants.

Individual difficulties in communicating their symptoms of illness and in perceiving a delay in being taken seriously by primary care practitioners echoed the well-documented difficulties of achieving a synergy between the 'voice of medicine' and the 'voice of the life world' or the patient's voice (Mishler 1984; Barry *et al.* 2001). Although often polarizations such as these can underplay the complexity of communication and the skilful work that patients do to get recognized.

Many participants chose to rationalize their difficulties in getting recognized as someone with a cancer in the context of their low expectations, given their demographic locale and the scarce resources. This was similarly reported in a recent interview study with people with cancer (Leydon *et al.* 2000), in which participants reported a 'charitable' approach to managing their cancer, where information and support were perceived as a rationed resource to be shared among many, some of whom will be 'worse-off'. This illuminates a NHS that appears to be very stretched, and is clearly perceived as such – to their possible disadvantage – by patients who are arguably most in need of it.

Gender was an important factor in participants' perspectives and their reported attitudes towards seeking help and in speaking about their symptoms. The roles articulated by participants evoked early theories of the 'affective' female and 'instrumental' male (Parsons 1951). Broad similarities existed, for men and women, the fear of having a serious illness was related to the perceived consequences for their ability to fulfil familial and broader social responsibilities, and to deal with the emotional impact of illness on those around them and the possible financial impact. Moynihan (1998) found that men identify being unable to take time off from work as a reason for delay or reluctance to confront serious illness. Men will often see women as having more time to go to the doctor. Becoming ill can represent weakness for men, sometimes resulting in the under-reporting of symptoms and pain levels to maintain a 'façade of strength' (Moynihan 1998). One possibly less attractive alternative might be to admit to fear and categorize oneself as a 'weakling', possibly preempting the anticipated ascription of such labels by others.

The importance of fear as a potential barrier to screening, uptake of services and optimal management of illness has been widely discussed in the cancer literature (Fitch *et al.* 2000; Foley 2000; Aro *et al.* 2001; Johnson 2001; Rees & Bath 2001). Fear sometimes prevented early health-seeking behaviour in participants faced with symptoms of illness. Some managed their fear of cancer and its associations with death and pain through avoiding contact or discussions with others about the illness. Others drew on idiomatic expressions of stoicism, positive thinking and fighting spirit (Wilkinson & Kitzinger 2000). Such positive thinking may be a double-edged sword. It may help patients to articulate their illness experiences and provide them with a way of coping with the fear of cancer on a day-to-day basis, but it may also too readily be perceived as a sign of not needing additional support or information. Space must be made for expressions of fear as well as stoicism for those who find it difficult to 'do' positive.

For some individuals, positive talk may arise out of a moral imperative to be positive and to 'fight' the cancer rather than a genuine 'behavioural' approach to managing the cancer experience (Wilkinson & Kitzinger 2000). Furthermore, on a methodological note, it is possible that for some an admission of a suspicion of cancer in the interview or elsewhere would somehow lead to blame on behalf of the patient, for example, for not acting on their suspicions more promptly. In other words, interviewees will attend to how they come across and will want to be perceived, as we all do, as responsible, morally accountable and reasonable (Baruch 1981). Healthcare providers need to be continually wary of these possibilities and tailor their approaches to recognizing genuine cases and to providing information and support accordingly.

It is clear that difficulties can and sometimes do exist during the pre-diagnostic journey and that the pre-diagnostic cancer journey is important at a service level and an individual patient level. Not only can it set the tone – good or bad – for the remainder of the illness experience, but its duration and nature may also have longer-term implications for access to treatment and, ultimately, for the patient's chances of survival.

In planning the delivery of information and support at all stages of the cancer journey, the social contexts, information preferences and information sources of patients need to be considered. Community-based religious, cultural and social organizations, the workplace, popular mainstream and ethnic media and social services should all be seen as powerful avenues of health promotion, more rapid detection of early symptoms, information provision and support.

We have attempted to elucidate some of the experiences of the journey towards diagnosis among individuals confronted with cancer and their significant others, some of whom also face disadvantage in other areas of their lives. Fear is overwhelmingly a barrier to early health-seeking behaviour. Current pathways may preclude a smooth and rapid transition from being a person with symptoms to becoming a patient with a confirmed cancer diagnosis. The importance of understanding these early experiences can best be conveyed by viewing them as foundational to the rest of the cancer journey. Some people will encounter great difficulty in communicating their symptoms to family and friends and, perhaps most importantly for the purpose of diagnosis, their doctors. Some who face concurrent long-standing illness or who have low expectations of their local health services because of a pervasive perception of under-resourcing may find prompt access difficult. These experiences will be pivotal to patient experiences along the entire illness path.

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Cancer patients' information needs and information seeking behaviour: in depth interview study

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Abstract

Objectives To explore why cancer patients do not want or seek information about their condition beyond that volunteered by their physicians at times during their illness.
Design Qualitative study based on in-depth interviews.
Setting Outpatient oncology clinics at a London cancer centre.
Participants 17 patients with cancer diagnosed in previous 6 months.
Main outcome measures Analysis of patients' narratives to identify key themes and categories.
Results While all patients wanted basic information on diagnosis and treatment, not all wanted further information at all stages of their illness. Three overarching attitudes to their management of cancer limited patients' desire for and subsequent efforts to obtain further information: faith, hope, and charity. Faith in their doctor's medical expertise precluded the need for patients to seek further information themselves. Hope was essential for patients to carry on with life as normal and could be maintained through silence and avoiding information, especially too detailed or "unsafe" information. Charity to fellow patients, especially those seen as more needy than themselves, was expressed in the recognition that scarce resources—including information and explanations—had to be shared and meant that limited information was accepted as inevitable.
Conclusions Cancer patients' attitudes to cancer and their strategies for coping with their illness can constrain their wish for information and their efforts to obtain it. In developing recommendations, the government's cancer information strategy should attend to variations in patients' desires for information and the reasons for them.

Introduction

Over recent years, communication and information have increasingly been considered important in helping people to cope with cancer.[1-5] A diagnosis of cancer may invoke uncertainty, fear, and loss that can be alleviated by information.[7-9] Research has indicated that the vast majority of cancer patients want to be informed about their illness.[5] However, it is also recognised that patients vary in how much information they want and that this may change during their illness. These attitudes are reflected in the efforts that patients make to obtain further information or to resist information that is offered to them.[10] In 1980 Ingelfinger, at that time an oncologist and editor of the *New England Journal of Medicine*, reported that when he discovered he had cancer he did not want all available information nor to have to face the uncertainties of the different treatment choices offered to him.[11] This hints at the complexity of providing information in oncology; information may be ignored or avoided by patients, regardless of their prior knowledge or occupation.

For those who provide care to cancer patients, the challenge is finding a way of providing information that is appropriate for patients who may benefit from knowing something about their illness and its treatment but may not wish to know everything about it at all times. This is particularly important in the light of the government's current commitment to build on the work of the Calman-Hine Expert Advisory Group to improve cancer care.[12] Recent developments include plans for a national cancer information strategy, the details of which have yet to be agreed. It is likely that such an initiative could include "core information packages" for all patients (NHS Information Authority, draft consultation document of cancer information strategy). In light of the move toward more formal provision of information, there is an urgent need to understand the ways that and the reasons why patients may choose not to seek or may resist further information about their cancer. This paper reports the findings of a study that explored patients' reasons for not wanting further information.

Participants and methods

Between November 1998 and February 1999, three physicians from a cancer centre identified patients whose cancer had been diagnosed in the previous six months and who were judged well enough to be interviewed. The first 24 patients who met these criteria were asked to participate in our study. Four of the patients declined (three men), and three others (two men) were too ill to be interviewed on the day of the appointment. Our study was approved by the ethics committee of the study site.

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Sociodemographic data were collected via a brief pre-interview questionnaire. In-depth interviews, focusing on the patients' experiences of information about their illness from first symptoms through to diagnosis and treatment, were carried out in the patient's home or the hospital. Each lasted between 45 and 90 minutes. Interviews were audiotaped, transcribed, and analysed according to the methods of framework analysis.[13] Developed by a specialist qualitative research unit called Social and Community Planning Research, framework analysis involves a systematic process of "sifting, charting and sorting material according to key issues and themes."[13] Transcripts were read repeatedly to identify the key themes and categories, which were then developed into a framework for coding the body of interview data. Multiple coding by GML, M Boulton, and CM tested the acceptability and reliability of the designated categories, and the validity of the coding was checked through deviant case analysis.[14]

Results

Sample characteristics

Of the 17 patients who completed the interview, 11 were women and six were men; 10 were non-manual workers, three were manual workers, and four were not classified; and 10 were white British, five were white other, and two were black British. Their median age was 55 years (range 28-79). The primary cancer diagnosed was breast cancer (4 cases), lymphoma (4), non-Hodgkin's lymphoma (2), lung cancer (2), and one case each of cancer of the colon, bladder, skin, brain, and liver. Two patients had a history of cancer.

Information about cancer and its treatment

All 17 patients interviewed had wanted basic information about diagnosis, treatment options, and common side effects of treatment. However, the timing of the desire for this information varied, as did the level of detail and content. Six patients had made efforts to obtain as much information as possible, but the remaining 11 patients reported minimal efforts to obtain information additional to that offered by hospital staff. All the interviews revealed a variability in attitude towards further information: patients did not want information about everything all of the time, but, at different times since their diagnosis, had wanted more or less information about particular aspects of their condition and its treatment.

Patients' attitudes towards seeking or accepting further information were based on their attitude to the management of their cancer. Systematic analysis of patient narratives revealed three overarching attitudes associated with a limited desire for and use of further information: faith, hope, and charity. Elements of faith, hope, and charity were present in all transcripts and affected information need and information seeking behaviour differently at different times.

Faith

To differing degrees, patients displayed faith in their doctors, and this contributed to their attitude toward seeking information beyond that volunteered by health professionals in routine interactions. Often such faith reflected an understanding of the complexity and medical uncertainty surrounding cancer and its treatment and ultimately reflected a will to live (see box 1, quote 1). Belief in the maxim that "doctor knows best" sometimes negated the perceived value of additional information, and patients believed (and some found) that additional information could confuse their situation. Having faith in their doctors' ability to successfully deploy what were often perceived as impressive and modern medical technologies often precluded information seeking.

Faith was clearly linked with the view that medical knowledge was difficult to understand. This was particularly the case among older patients, who, because they felt their knowledge and understanding of medicine was limited, believed that additional searching could be dangerous and exacerbate an already difficult situation (box 1, quote 2).

Some, who spoke of their faith in their doctors' expertise, expressed concern that information seeking might be perceived as transgressing their incumbent role as patient. Being a good patient was construed as "doing as you are told" and being a "good customer," as opposed to knowing a lot and being inquisitive (box 1, quote 3). For most patients, this perception of themselves as apparently disempowered was rationalised and placed in a favourable light by relying on and having faith in their doctors' expertise. For most, placing their faith in their doctors' hands was a strategy that could change at a later stage depending on various factors, including the course of the disease and the need to maintain a sense of hope (box 1, quote 4).

Box 1: Faith

1. "I didn't know what to expect with the treatment, I was optimistic. I couldn't even think about how I could do chemotherapy. I prepared my mind for whatever it takes, [to] follow the rules of the experts; they have said that this is what I've go to do to get better, and I've got to—whatever way, shape, or form—get better." (Interview 10: 45 year old man with lymphoma)

2. "To be honest, when they said to me it's cancer I thought I'll put it in their hands now because sometimes it can be a dangerous thing when you start listening and looking. We only have a certain amount of intellect, and we only have a certain amount of education. There is nothing like an ignorant man trying to learn and know every little thing about it. With regards to medicine and the like, the less you know the better." (Interview 12: 74 year old man with skin cancer)

3. "Maybe they don't tell you everything—all the side effects—because they think it will frighten you. But if you read it yourself they probably think, 'Clever dick,' for finding out. They probably think, 'She should be listening to us'. I don't think they particularly like you bringing up ideas, not that much, not really." (Interview 11: 64 year old woman with brain cancer)

4. "I don't want to use information lines and things like that at the moment. I'm working on my principle that ignorance is bliss. I am not denying the situation I am in, but I am not speaking to people like that at the moment, I don't feel I need to. At the moment I get what I want, but not too much detail. Further down the line it may change, depending on which way it goes, if it's bad." (Interview 5: 44 year old man with liver cancer, melanoma of the eye seven years earlier)

Hope

A sense of hope pervaded all 17 narratives, and for some this was closely linked to fear. Patients created a facade of hopefulness, often in the most advanced cases (box 2, quote 1). Hope was indispensable for survival, and this interacted with information seeking in a complex way. For some it meant avid searching for information, particularly about alternative treatments, but for others it meant limited searching for or even avoidance of new information. Immediately after diagnosis, patients needed to be enabled to ask questions and search for information; without basic diagnostic information, attempts to find out additional information were often thwarted (box 2, quote 2).

At different times during their illness patients halted their information seeking because of fearful and contradictory information, often a consequence of genuine medical uncertainties. These periods of self censorship functioned to preserve hope by avoiding negative information about their illness and in turn helped to manage their fears associated with the potential of a negative outcome (see box 2, quote 3).

Contradictory information was a source of anxiety for most patients, as it often confused treatment decisions already made. Weighing evidence and deciding on the best course of action was difficult, even with a medical background. Depending on the immediacy of the issue, some patients resolved the conflict of contradictory information by calling on other patients and lay contacts (including medical friends) to judge between conflicting accounts (box 2, quotes 3 and 4).

Women patients often valued the knowledge and experience of other cancer patients more than medical information, and this personal experience often proved invaluable with treatment decision making. By contrast, the men rarely spoke of relying on the experience of other patients; once they left the outpatient clinic or treatment room they preferred a policy of "life as normal" in which cancer could be forgotten (at least superficially).

Additional information could exacerbate fear and threaten to undermine patients' hopes. Even basic introductory booklets could be frightening, and consequently some patients truncated their efforts to find out more (box 2, quotes 2 and 5). Patients were also aware that literature produced for patients "in general" was not necessarily relevant to every individual, and the difficulty of discerning information germane to their own individual situations was clearly frustrating (box 2, quote 6).

To avoid the risk of uncovering information that could threaten their hope, some enlisted the help of others in finding out new material. Not everyone had access to proxy informants, however, and those too fearful to assimilate additional information avoided all information sources. Emotive media coverage of "cancer victims" such as Linda McCartney rendered avoidance difficult at times and for some constituted an unwelcome threat to hope (box 2, quote 7).

The expression of hope often entailed presenting a brave face to others, and this could itself make it difficult to talk about or seek information regarding cancer. Getting on with life and maintaining a positive outlook was perceived as the approach to managing illness that was most respected by hospital staff, friends, and family. Asking for information beyond the basic details of the diagnosis and side effects of treatment could undermine patients' positive appearance. The pressure to present a hopeful facade also related to a fear of using up any reserve of sympathy and support from friends and relatives (box 2, quote 8).

The pressure to preserve a brave face and the linked pressure to avoid information about the illness was more common among men, who maintained hope through silence. Men in particular preferred not to ask questions of the medical profession, or people in their wider social networks, so as to avoid discussions of disease recurrence and, ultimately, death. Efforts to maintain hope could thus drive out interest in finding out further information.

Box 2: Hope

1. "Fortunately, I've got the slow growing one; the counsellor drew a diagram for me (shows diagram to GML). So she said there was the tumour there [breast], there's the other one there [lung], and then they found a very small one on the top [brain]. So I could actually feel where everything was, which was good, but then also in the fluid going round the brain and down the spinal cord. The doctor said there are other [treatments] if this one doesn't work, so the way I am looking at it is it's either going to be good, and I don't know what happens after that, or if it isn't there are other options. Where there are other options, there is still hope." (Interview 3: 54 year old woman with primary breast cancer and multiple metastases)

2. "I found out what I had by reading my notes on the way up to x ray. A high or low grade, T or B cell lymphoma. It's no good anyway, because I don't know the difference. Information is difficult in the beginning because I couldn't look at the relevant bits, so it's better to be told your exact diagnosis as soon as possible, otherwise even general booklets are too scary and too detailed—my boyfriend looks for me." (Interview 2: 28 year old woman with non-Hodgkin's lymphoma)

3. "In the end I got so confused and one woman had such an influence on me that I was moving very fast in the direction of thinking I would have chemotherapy, and I wasn't too keen to get too much input that was going to suggest I shouldn't. I think I consciously censored myself. I didn't look chemotherapy up on the internet; I just have recently, and it's really shaken me." (Interview 1: 48 year old woman with breast cancer)

4. "It's very difficult making treatment decisions because of the contradictory information, and it's very difficult not being a medical person. It was this woman in the end who helped me decide. She didn't try to persuade me, but it was something about the reasons she gave, you know, regretting not doing it in the future if I get cancer again. Secretly I think I knew I was going to do it [have chemotherapy], and I didn't want to find out too much negative information." (Interview 1: 48 year old woman with breast cancer)

5. "The thing with these leaflets—I mean, I did start to read a few, but then when you read them you get information, but I think they give you a bit too much about what it's going to do and where it can go. I know I have it, and that's all I want to know." (Interview 9: 60 year old man with liver cancer)

6. "I was trying to find information about what treatments are available and things like that, but I kept on finding that every person is different, so I found that trying to find out the different grades and things was difficult. I don't think you can find an answer actually that will satisfy you .... I think I've found my way of coping through God—just pray, pray, pray." (Interview 4: 46 year old woman with breast cancer)

7. "Trouble was I used to buy a newspaper every day in hospital, and every day cancer—always somebody who had bravely died of cancer. I was a bit cross, and I nearly wrote to the [newspaper] because it was every day, and I thought, 'Well, what about all those people who bravely live?'" (Interview 6: 64 year old woman with non-Hodgkin's lymphoma)

8. "Friends and family expect you to be depressed and talk about it, but if you're all doom and gloom people won't want to come near you, and you need people. This is why you tend to switch off a bit and just have a bloody good laugh when people come to see you, because then they'll want to come back to see you." (Interview 3: 54 year old woman with primary breast cancer and multiple metastases)

Charity

Even in the face of their adversity, all the patients reported having been influenced by thoughts of others whom they perceived to be worse off or more needy than themselves. As with other NHS resources, information—or access to those who could provide it—was seen as a limited resource, rationed among all patients (box 3, quote 1).

Frequent references were made to the usefulness of the clinic consultation for getting reassurance, which was vital for maintaining hope, and obtaining help in interpreting additional information from independent sources. None the less, patients expressed concern about taking up too much of their doctors' time when other patients were waiting to be seen in the outpatient clinic (box 3, quote 2). These sentiments were more evident among those patients with close friends or family (most of our sample), who perceived patients without such support to be more needy and deserving of information (box 3, quote 3).

By making comparisons with others, patients could see that their situation was better than that of others. However, this favourable comparison could then be seen as weakening their claim for scarce resources and giving precedence to the claim of others.

Some found it easier to accept information obtained by friends and relatives because they had not personally used a scarce resource. Similarly, patients clearly found information easier to accept when it was verbally offered by hospital staff rather than having to ask for additional information themselves. Others, however, pointed to the legitimate needs of their fellow patients in explaining their reluctance to make further demands on the time and resources of doctors and nurses in the clinics.

Discussion

We have investigated an observation commonly made by those who provide care to cancer patients, that not all patients want extensive information about their condition and treatment at all stages of their illness. Though not based on a statistically representative sample, this study provides insights into the reasons underlying patients not seeking information at particular times during their illness within six months of diagnosis.

Box 3: Charity

1. "I got information on home nursing, and they came round, but I stopped them in the end. Not because I didn't want them, but, after I started on my chemotherapy, they used to pop around to see how I was, but I seemed to be doing okay . . . so I said to them it's best to just 'phone me. I said there's probably other people who needed to see them more than me." (Interview 9: 58 year old man with liver cancer)

2. "The consultant said, 'Have you got any questions?' and I had, but I felt that there was this huge waiting room filled with people. I had written them down, but I then felt very conscious of the fact that the consultant had this enormous pressure of people outside. There was a lot of talk among the nurses about how many people there were, so I knew I had to rush." (Interview 1: 48 year old woman with breast cancer)

3. "I haven't used telephone lines or anything like that. I have support from the family, and there are people who have got nobody at all, so why should I bother them when I've got people that I can call on?" (Interview 12: 74 year old man with skin cancer)

Limitations of study

Qualitative methods often dictate small samples, and personal interviews could skew the sample towards patients who find it easier to talk about their illness. The constraints imposed on the recruitment process by the setting of a busy clinic in a cancer centre meant that it would have been impossible to sample purposively. Fortunately, however, the final sample comprised patients with a range of sociodemographic backgrounds, cancer types, and experiences of illness. The similarities between some of our core themes and those found in other studies[10] permits confidence in the validity of our data and analysis of the data.

A longitudinal, prospective study could avoid the limitations of single retrospective interviews. A longitudinal approach could also maximise the ability to explore and map out the fluid and changing nature of patients' orientations to the management of their cancer and their subsequent efforts to obtain (and avoid) additional illness information over time. A survey study to assess the generalisability of some of the key findings from this interview study, in particular the determinants of information preference and access to information, such as gender and age, will be reported at a later date.

Reasons for not seeking information

Our study shows that in our apparently "patient centred" era some patients (particularly older patients and men) still adopt a non-participatory role in the management of their illness.[1 15 16] In the 1950s Parsons argued that the nature of the roles of patients derived from the faith placed in doctors' medical expertise.[17] These perceptions still exist and influence patients' need for and seeking of information. Wanting to be seen as a "good customer," trusting what a doctor says, and "ignorance" and the consequent (perceived) inability to assimilate medical information are important reasons for patients' non-use of information. Arguably, older patients would have grown up in an era characterised by "doctor centred" practice,[18] and this may help to explain the greater use of independent information services by younger patients.[19 20]

Men seemed to be less likely to access additional information services, and the next phase of our research will focus on these sex differences. Men maintained hope through silence and, more generally, "strength in silence" (C Moynihan et al, "Strength in silence: men and cancer," British psychosocial oncology conference, Royal College of Physicians, London, 1999), and this influenced their desire for information at different times during their illness. The value of hope in the management of chronic illness is well established,[21 22] but our study has shown the complexity of the relationship between hope and a patient's desire for information.[23] Hope and fear are intertwined, and patients oscillate between the desire for more information and the avoidance of new information. Hope might be accomplished and maintained through silence, periods of self censorship, and not searching for information or searching by proxy, and these

strategies enable patients to circumvent negative information about their illness, which poses a constant threat to hope. As Ruth Pinder found in her study of Parkinson's disease, "knowledge of what the clinical facts mean is not always the priceless resource other writers [suggest]. Sometimes it is too threatening"[16]

Finally, we found that patients' behaviour was influenced by consideration of the needs of other patients. This attitude of charity reflected patients' perceptions of a rationed health service and helped to rationalise their having minimal information. This attitude has received little attention in the context of cancer patients (S Morris, medical sociology conference, York, 1998) and should become an increasingly important consideration as rationing becomes more widely acknowledged in the NHS.

Patients' preferences for information derives from the coping strategy or attitude they have to managing their cancer. While all patients have the right to information, they will wish to use this right to varying degrees at different times. Health service providers need to continuously assess whether each individual patient wants only limited information or whether external constraints such as a language barrier, clinic organisation, or the attitudes of health professionals deny them access to the information they want.

Conclusions

The factors affecting patients' uptake of information services are complex. Patients' orientations toward faith, hope and charity may mean, at points on the illness path they may prefer to avoid disease related information and may choose not to use cancer information services. An understanding of the reasons why patients may want only limited information can help to ensure that the national strategy being developed is flexible and responsive to individual's coping strategies and information choices.

We thank all those who participated in the interviews and their physicians who facilitated recruitment, the Cancer Research Campaign for funding the study, Dr Judith Green for valuable discussions, and the Steering Committee for their dedication to the project.

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What is already known on this topic

Although cancer patients want to be informed about their illness, not all patients want extensive information about their condition and treatment at all stages of their illness

The reasons why patients vary in how much information they want have been little explored

What this study adds

In-depth interviews with 17 cancer patients showed they had three overarching attitudes to their cancer and strategies for coping with it that limited their wish for further information: faith, hope, and charity

Faith in doctors' medical expertise precluded the need for further information; hope was considered essential for coping and could be maintained by avoiding potentially negative information; and charity to fellow patients included the recognition that scarce resources (including information and explanations) had to be shared and meant that limited information was accepted as inevitable

Corrections and clarifications

Obituaries

The original wording of Dr Maureen Seddon's obituary (4 March, p 652) mentioned her patience in dealing with the "most troubled families." We apologise that in the editing process this was foolishly translated into the "most troublesome families."

A wrong date crept into the obituary of Dr William Deane Steele (5 February, p 385). He settled in Worcester in 1931, not 1928.

Gout

Some terminology in this editorial by R D Sturrock (15 January, pp 132-3) may have confused readers. Firstly, we should have converted the target urate level cited in the final paragraph to SI units: the level should have appeared as 250-450 μmol/l (not 40-70 mg/l). Secondly, some of our younger readers might have been puzzled by the word "podagra" in the first paragraph. The term "gouty pain in the great toe" might have been clearer.

Editor's Pick

My 94-year-old grandmother has metastatic breast cancer, although she does not know the diagnosis. She knows that she is ill, and doesn't want to live forever. She is still mentally alert, holds strong opinions about almost everything, and wants to make her own choices. But what should she be told?

Does detailed information about diagnosis and prognosis empower people or push them into a state of hopelessness, despair, and premature death? Doctors used to adopt a paternalistic approach, sheltering their patients from the details surrounding their illness. They would concoct stories to disguise the truth, making unilateral decisions about was "best" for them.

Slowly, things have changed. Standard practice now requires that mentally competent people be involved in decision-making, thus necessitating discussions of diagnosis. Many patients want to know exactly what is happening to them. Ironically, doctors practicing in our new "health care environment" don't know their patients for a long enough time to provide tailored information. There are many reasons why we don't know our patients the way we used to, including the regularly changing menu of health plans and an increasingly mobile society. But does it matter?

In this month's *wjm*, Leydon and colleagues (p 26) offer some insight based on interviews with 17 newly diagnosed cancer patients. While all patients wanted to know their diagnosis and treatment options, this is all that they had in common. Some wanted specific details with statistics, while others wanted only a summary or very little information at all. The authors found that people's attitudes toward 3 areas—faith in the medical profession, hope, and concern for others—predicted their desires for specific information.

What will my grandmother do with the information that she has cancer? She may ignore it. On the other hand, she may decide to fight the cancer, but I doubt it. It is far more likely that she will accept it, without surprise. Some studies suggest that this type of acceptance may lead to an earlier death compared with denial or a "fighting" approach. But the choice is hers. It is then our duty both as physicians and fellow humans to support her decision and provide compassion, care, and support.

COMMENTARY

What cancer patients want to know: national strategies and individual needs

Leydon and her colleagues present a provocative analysis of the information needs and information-seeking behavior of 17 cancer patients in a London oncology clinic. Through careful framework analysis of patient interviews, the authors identify 3 themes to explain the common observation that different patients want different amounts of information at different times during their illness. Faith in physician expertise, the threat that bad news can impose on hope, and a sense of charity toward the needs of sicker patients appear to limit these cancer patients' pursuit of information. The authors present their findings in the context of exploring a national health care information strategy for cancer patients.

In helping to better understand the needs of vulnerable patients, this well-done study serves an important function. However, it is a qualitative study of a small number of patients in London, so the generalizability of its conclusions must be questioned. The study's findings may not apply to patients from other demographic backgrounds and to populations outside England.

Information-seeking, hope, and support issues appear to be different for men and women and vary according to the age of the patient. The authors promise an evaluation of sex differences in a forthcoming study. Other demographic issues that should be explored include language, race, ethnicity, economic status, and education level. Other sources of belief and understanding, such as religious faith and social support, are also likely to be important.

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Faith, hope, and charity: an in-depth interview study of cancer patients' information needs and information-seeking behavior

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ABSTRACT **Objective** To explore why cancer patients do not want or seek information about their condition beyond that volunteered by their physicians at times during their illness. **Design** Qualitative study based on in-depth interviews. **Setting** Outpatient oncology clinics at a London cancer center. **Participants** 17 patients with cancer diagnosed in previous 6 months. **Main outcome measures** Analysis of patients' narratives to identify key themes and categories. **Results** While all patients wanted basic information on diagnosis and treatment, not all wanted further information at all stages of their illness. Three overarching attitudes to their management of cancer limited patients' desire for and subsequent efforts to obtain further information: faith, hope, and charity. Faith in their doctor's medical expertise precluded the need for patients to seek further information themselves. Hope was essential for patients to carry on with life as normal and could be maintained through silence and avoiding information, especially too detailed or "unsafe" information. Charity to fellow patients, especially those seen as more needy than themselves, was expressed in the recognition that scarce resources—including information and explanations—had to be shared and meant that limited information was accepted as inevitable. **Conclusions** Cancer patients' attitudes to cancer and their strategies for coping with their illness can constrain their wish for information and their efforts to obtain it. In developing recommendations, the government's cancer information strategy should attend to variations in patients' desires for information and the reasons for them.

INTRODUCTION

Over recent years, communication and information have increasingly been considered important in helping people to cope with cancer.[1-6] A diagnosis of cancer may invoke uncertainty, fear, and loss that can be alleviated by information.[7-9] Research has indicated that the majority of cancer patients want to be informed about their illness.[5] It is also recognized, however, that patients vary in how much information they want and that this may change during their illness. These attitudes are reflected in the efforts that patients make to obtain further information or to resist information that is offered to them.[10] In 1980, when he was an oncologist and editor of the *New England Journal of Medicine*, Ingelfinger reported that when he discovered he had cancer, he did not want all available information nor have to face the uncertainties of the different treatment choices offered to him.[11] This hints at the complexity of providing information in oncology; information may be ignored or avoided by patients, regardless of their prior knowledge or occupation.

For those who provide care to cancer patients, the challenge is finding a way of providing information that is appropriate for patients who may benefit from knowing something about their illness and its treatment but may not wish to know everything about it at all times. This challenge is particularly important in light of the government's current commitment to build on the work of the Calman-Hine Expert Advisory Group to improve cancer care.[12] Recent developments include plans for a national cancer information strategy, the details of which have yet to be agreed. It is likely that such an initiative could include "core information packages" for all patients (NHS Information Authority, draft consultation document of cancer information strategy). In light of the move toward more formal provision of information, there is an urgent need to understand the ways that and the reasons why patients may choose not to seek or may resist further information about their cancer. This paper reports the

- Although cancer patients want to be informed about their illness, not all patients want extensive information about their condition and treatment at all stages of their illness
- Reasons why patients vary in how much they want to know relates to their strategies for coping with their illness
- Faith in doctors' medical expertise precluded the need for further information
- Hope is considered essential for coping and could be maintained by avoiding potentially negative information
- Charity to fellow patients included recognizing that scarce resources had to be shared

findings of a study that explored patients' reasons for not wanting further information.

PARTICIPANTS AND METHODS

Between November 1998 and February 1999, 3 physicians from a cancer center identified patients whose cancer had been diagnosed in the previous 6 months and who were judged well enough to be interviewed. The first 24 patients who met these criteria were asked to participate in our study. Four of the patients declined (3 men), and 3 others (2 men) were too ill to be interviewed on the day of the appointment. Our study was approved by the ethics committee of the study site.

Sociodemographic data were collected using a brief pre-interview questionnaire. In-depth interviews, focusing on the patients' experiences of information about their illness from first symptoms through to diagnosis and treatment, were carried out in the patient's home or the hospital. Each lasted between 45 and 90 minutes. Interviews were audiotaped, transcribed, and analyzed according to the methods of framework analysis.[13] Developed by a specialist qualitative research unit called Social and Community Planning Research, framework analysis involves a systematic process of "sifting, charting and sorting material according to key issues and themes."[13] Transcripts were read repeatedly to identify the key themes and categories, which were then developed into a framework for coding the body of interview data. Multiple coding by 3 of us (GML, MB, and CM) tested the acceptability and reliability of the designated categories, and the validity of the coding was checked through deviant case analysis.[14]

RESULTS

Sample characteristics

Of the 17 patients who completed the interview, 11 were women and 6 were men; 10 were non-manual workers, 3 were manual workers, and 4 were not classified; and 10 were white British, 5 were white other, and 2 were black British. Their median age was 55 years (range 28 to 79). The primary cancer diagnosed was breast cancer (4 cases), lymphoma (4), non-Hodgkin's lymphoma (2), lung cancer (2), and 1 case each of cancer of the colon, bladder, skin, brain, and liver. Two patients had a history of cancer.

Information about cancer and its treatment

All 17 patients interviewed had wanted basic information about diagnosis, treatment options, and common side effects of treatment. The timing of the desire for this information varied, however, as did the level of detail and content. Six patients had made efforts to obtain as much information as possible, but the remaining 11 patients reported minimal efforts to obtain information additional to that offered by hospital staff. All the interviews revealed a variability in attitude toward further information: patients did not want information about everything all of the time, but, at different times since their diagnosis, had wanted more or less information about particular aspects of their condition and its treatment.

Patients' attitudes toward seeking or accepting further information were based on their attitude to the management of their cancer. Systematic analysis of patient narratives revealed three overarching attitudes associated with a limited desire for and use of further information: faith, hope, and charity. Elements of faith, hope, and charity were present in all transcripts and affected information need and information-seeking behavior differently at different times.

Faith

To differing degrees, patients displayed faith in their doctors, and this contributed to their attitude toward seeking information beyond that volunteered by health professionals in routine interactions. Often such faith reflected an understanding of the complexity and medical uncertainty surrounding cancer and its treatment and ultimately reflected a will to live (see box, quote 1). Belief in the maxim that "doctor knows best" sometimes negated the perceived value of additional information, and patients believed (and some found) that additional information could confuse their situation. Having faith in their doctors' ability to successfully deploy what were often perceived as impressive and modern medical technologies often precluded information seeking.

Faith was clearly linked with the view that medical knowledge was difficult to understand. This was particularly the case among older patients, who, because they felt their knowledge and understanding of medicine was limited, believed that additional searching could be dangerous and exacerbate an already difficult situation (see box, quote 2).

Some who spoke of their faith in their doctors' expertise expressed concern that information seeking might be perceived as transgressing their incumbent role as patient. Being a good patient was construed as "doing as you are told" and being a "good customer," as opposed to knowing a lot and being inquisitive (see box, quote 3). For most patients, this perception of themselves as apparently disempowered was rationalized and placed in a favorable light by relying on and having faith in their doctors' expertise. For most, placing their faith in their doctors' hands was a strategy that could change at a later stage depending on various factors, including the course of the disease and the need to maintain a sense of hope (see box, quote 4).

1 "I didn't know what to expect with the treatment, I was optimistic. I couldn't even think about how I could do chemotherapy. I prepared my mind for whatever it takes, [to] follow the rules of the experts; they have said that this is what I've go to do to get better, and I've got to—whatever way, shape, or form—get better." (Interview 10: 45-year-old man with lymphoma.)

2 "To be honest, when they said to me it's cancer, I thought I'll put it in their hands now because sometimes it can be a dangerous thing when you start listening and looking. We only have a certain amount of intellect, and we only have a certain amount of education. There is nothing like an ignorant man trying to learn and know every little thing about it. With regards to medicine and the like, the less you know, the better." (Interview 12: 74-year-old man with skin cancer.)

3 "Maybe they don't tell you everything—all the side effects—because they think it will frighten you. But if you read it yourself, they probably think, 'Clever woman,' for finding out. They probably think, 'She should be listening to us.' I don't think they particularly like you bringing up ideas, not that much, not really." (Interview 11: 64-year-old woman with brain cancer.)

4 "I don't want to use information lines and things like that at the moment. I'm working on my principle that ignorance is bliss. I am not denying the situation I am in, but I am not speaking to people like that at the moment, I don't feel I need to. At the moment, I get what I want, but not too much detail. Further down the line, it may change, depending on which way it goes, if it's bad." (Interview 5: 44-year-old man with liver cancer, melanoma of the eye 7 years earlier.)

Hope

A sense of hope pervaded all 17 narratives, and for some this was closely linked to fear. Patients created a facade of hopefulness, often in the most advanced cases (see box, quote 1). Hope was indispensable for survival, and this interacted with information seeking in a complex way. For some, it meant avid searching for information, particularly about alternative treatments, but for others, it meant limited searching for or even avoidance of new information. Immediately after diagnosis, patients needed to be enabled to ask questions and search for information; without basic diagnostic information, attempts to find out additional information were often thwarted (see box, quote 2).

At different times during their illness, patients halted their information seeking because of fearful and contradictory information, often a consequence of genuine medical uncertainties. These periods of self-censorship functioned to preserve hope by avoiding negative information about their illness and in turn helped to manage their fears associated with the potential of a negative outcome (see box, quote 3).

Contradictory information was a source of anxiety for most patients, as it often confused treatment decisions already made. Weighing evidence and deciding on the best course of action was difficult, even with a medical background. Depending on the immediacy of the issue, some patients resolved the conflict of contradictory information by calling on other patients and lay contacts (including medical friends) to judge between conflicting accounts (see box, quotes 3 and 4).

Women patients often valued the knowledge and experience of other cancer patients more than medical information, and this personal experience often proved invaluable for making a decision about treatment. By contrast, the men rarely spoke of relying on the experience of other patients; once they left the outpatient clinic or treatment room, they preferred a policy of "life as normal" in which cancer could be forgotten (at least superficially).

Additional information could exacerbate fear and threaten to undermine patients' hopes. Even basic introductory booklets could be frightening; consequently, some patients truncated their efforts to find out more (see box, quotes 2 and 5). Patients were also aware that literature produced for patients "in general" was not necessarily relevant to every individual, and the difficulty of discerning information germane to their own individual situations was clearly frustrating (see box, quote 6).

To avoid the risk of uncovering information that could threaten their hope, some enlisted the help of others in finding out new material. Not everyone had access to proxy informants, however, and those too fearful to assimilate additional information avoided all information sources. Emotive media coverage of "cancer victims" such as Linda McCartney rendered avoidance difficult at times and for some constituted an unwelcome threat to hope (see box, quote 7).

The expression of hope often entailed presenting a brave face to others, and this could itself make it difficult to talk about or seek information regarding cancer. Getting on with life and maintaining a positive outlook was perceived as the approach to managing illness that was most respected by hospital staff, friends, and family. Asking for information beyond the basic details of the diagnosis and side effects of treatment could undermine patients' positive appearance. The pressure to present a hopeful facade also related to a fear of using up any reserve of sympathy and support from friends and relatives (see box, quote 8).

The pressure to preserve a brave face and the linked pressure to avoid information about the illness was more common among men, who maintained hope through silence. Men in particular preferred not to ask questions of the medical profession, or people in their wider social networks, so as to avoid discussions of disease recurrence and, ultimately, death. Efforts to maintain hope could thus drive out interest in finding out further information.

1 "Fortunately, I've got the slow-growing one; the counselor drew a diagram for me (shows diagram to GML). So she said there was the tumor there [breast], there's the other one there [lung], and then they found a very small one on the top [brain]. So I could actually feel where everything was, which was good, but then also in the fluid going round the brain and down the spinal cord. The doctor said there are other [treatments] if this one doesn't work, so the way I am looking at it is, it's either going to be good, and I don't know what happens after that, or if it isn't, there are other options. Where there are other options, there is still hope." (Interview 3: 54-year-old woman with primary breast cancer and multiple metastases.)

2 "I found out what I had by reading my notes on the way up to X-ray. A high- or low-grade, T or B cell lymphoma. It's no good anyway, because I don't know the difference. Information is difficult in the beginning because I couldn't look at the relevant bits, so it's better to be told your exact diagnosis as soon as possible, otherwise even general booklets are too scary and too detailed—my boyfriend looks for me." (Interview 2: 28-year-old woman with non-Hodgkin's lymphoma.)

3 "In the end, I got so confused and one woman had such an influence on me that I was moving very fast in the direction of thinking I would have chemotherapy, and I wasn't too keen to get too much input that was going to suggest I shouldn't. I think I consciously censored myself. I didn't look chemotherapy up on the Internet; I just have recently, and it's really shaken me." (Interview 1: 48-year-old woman with breast cancer.)

4 "It's very difficult making treatment decisions because of the contradictory information, and it's very difficult not being a medical person. It was this woman in the end who helped me decide. She didn't try to persuade me, but it was something about the reasons she gave, you know, regretting not doing it in the future if I get cancer again. Secretly, I think I knew I was going to do it [have chemotherapy], and I didn't want to find out too much negative information." (Interview 1: 48-year-old woman with breast cancer.)

5 "The thing with these leaflets—I mean, I did start to read a few— but then when you read them you get information, but I think they give you a bit too much about what it's going to do and where it can go. I know I have it, and that's all I want to know." (Interview 9: 60-year-old man with liver cancer.)

6 "I was trying to find information about what treatments are available and things like that, but I kept on finding that every person is different, so I found that trying to find out the different grades and things was difficult. I don't think you can find an answer actually that will satisfy you . . . . I think I've found my way of coping through God—just pray, pray, pray." (Interview 4: 46-year-old woman with breast cancer.)

7 "Trouble was, I used to buy a newspaper every day in hospital, and every day cancer—always somebody who had bravely died of cancer. I was a bit cross, and I nearly wrote to the [newspaper] because it was every day, and I thought, 'Well, what about all those people who bravely live?' " (Interview 6: 64-year-old woman with non-Hodgkin's lymphoma.)

8 "Friends and family expect you to be depressed and talk about it, but if you're all doom and gloom, people won't want to come near you, and you need people. This is why you tend to switch off a bit and just have a good laugh when people come to see you, because then they'll want to come back to see you." (Interview 3: 54-year-old woman with primary breast cancer and multiple metastases.)

Charity

Even in the face of their adversity, all the patients reported having been influenced by thoughts of others whom they perceived to be worse off or more needy than themselves. As with other health system resources, information—or access to those who could provide it—was seen as a limited resource, rationed among all patients (see box, quote 1).

Frequent references were made to the usefulness of the clinic consultation for getting reassurance, which was vital for maintaining hope, and obtaining help in interpreting additional information from independent sources. Nonetheless, patients expressed concern about taking up too much of their doctors' time when other patients were waiting to be seen in the outpatient clinic (see box, quote 2). These sentiments were more evident among those patients with close friends or family (most of our sample), who perceived patients without such support to be more needy and deserving of information (see box, quote 3).

By making comparisons with others, patients could see that their situation was better than that of others. This favorable comparison, however, could then be seen as weakening their claim for scarce resources and giving precedence to the claim of others.

Some found it easier to accept information obtained by friends and relatives because they had not personally used a scarce resource. Similarly, patients clearly found information easier to accept when it was verbally offered by hospital staff rather than having to ask for additional information themselves. Others, however, pointed to the legitimate needs of their fellow patients in explaining their reluctance to make further demands on the time and resources of doctors and nurses in the clinics.

DISCUSSION

We have investigated an observation commonly made by those who provide care to cancer patients that not all patients want extensive information about their con-

1 "I got information on home nursing, and they came round, but I stopped them in the end. Not because I didn't want them, but after I started on my chemotherapy, they used to pop around to see how I was, but I seemed to be doing okay . . . so I said to them, It's best to just 'phone me. I said there's probably other people who needed to see them more than me." (Interview 9: 58-year-old man with liver cancer.)

2 "The consultant said, 'Have you got any questions?' and I had, but I felt that there was this huge waiting room filled with people. I had written them down, but I then felt very conscious of the fact that the consultant had this enormous pressure of people outside. There was a lot of talk among the nurses about how many people there were, so I knew I had to rush." (Interview 1: 48-year-old woman with breast cancer.)

3 "I haven't used telephone lines or anything like that. I have support from the family, and there are people who have got nobody at all, so why should I bother them when I've got people that I can call on?" (Interview 12: 74-year-old man with skin cancer.)

dition and treatment at all stages of their illness. Although not based on a statistically representative sample, this study provides insights into the reasons underlying patients not seeking for information at particular times during their illness within 6 months of diagnosis.

Limitations of the study

Qualitative methods often dictate small samples, and personal interviews could skew the sample toward patients who find it easier to talk about their illness. The constraints imposed on the recruitment process by the setting of a busy clinic in a cancer center meant that it would have been impossible to sample purposively. Fortunately, however, the final sample comprised patients with a range of sociodemographic backgrounds, cancer types, and experiences of illness. The similarities between some of our core themes and those found in other studies[10] permits confidence in the validity of our data and analysis of the data.

A longitudinal, prospective study could avoid the limitations of single retrospective interviews. A longitudinal approach could also maximize the ability to explore and map out the fluid and changing nature of patients' orientations to the management of their cancer and their subsequent efforts to obtain (and avoid) additional illness information over time. A survey study to assess the generalizability of some of the key findings from this interview study, in particular the determinants of information preference and access to information, such as gender and age, will be reported at a later date.

Reasons for not seeking information

Our study shows that in our apparently "patient-centered" era, some patients (particularly older patients and men) still adopt a nonparticipatory role in the management of their illness.[1,15,16] In the 1950s, Parsons argued that the nature of the roles of patients derived from the faith placed in doctors' medical expertise.[17] These perceptions still exist and influence patients' need for and seeking of information. Wanting to be seen as a "good customer," trusting what a doctor says, and "ignorance" and the consequent (perceived) inability to assimilate medical information are important reasons for patients' non-use of information. Arguably, older patients would have grown up in an era characterized by "doctor-centered" practice,[18] and this may help to explain the greater use of independent information services by younger patients.[19,20]

Men seemed to be less likely to access additional information services, and the next phase of our research will focus on these sex differences. Men maintained hope through silence and, more generally, "strength in silence" (C Moynihan et al, *Strength in Silence: Men and Cancer*, British Psychosocial Oncology Conference, Royal College of Physicians, London, 1999), and this influenced their desire for information at different times during their illness. The value of hope in the management of chronic illness is well established,[21,22] but our study has shown the complexity of the relationship between hope and a patient's desire for information.[23] Hope and fear are intertwined, and patients oscillate between the desire for more information and the avoidance of new information. Hope might be accomplished and maintained through silence, periods of self-censorship, and not searching for information or searching by proxy, and these strategies enable patients to circumvent negative information about their illness, which poses a constant threat to hope. As Pinder found in her study of Parkinson's disease, "knowledge of what the clinical facts mean is not always the priceless resource other writers [suggest]. Sometimes it is too threatening."[10]

Finally, we found that patients' behavior was influenced by consideration of the needs of other patients. This attitude of charity reflected patients' perceptions of a rationed health service and helped to rationalize their having minimal information. This attitude has received little attention in the context of cancer patients (S Morris, Medical Sociology Conference, York, 1998) and should become an increasingly important consideration as rationing becomes more widely acknowledged.

Patients' preferences for information derives from the coping strategy or attitude they have to managing their cancer. While all patients have the right to information, they will wish to use this right to varying degrees at different times. Health service providers need to continuously assess whether each individual patient wants only

limited information or whether external constraints such as a language barrier, clinic organization, or the attitudes of health professionals deny them access to the information they want.

CONCLUSIONS

The factors affecting patients' uptake of information services are complex. Patient orientations toward faith, hope, and charity may mean, at points on the illness path, that patients may prefer to avoid disease-related information and may choose to not use cancer information services. An understanding of the reasons why patients may want only limited information can help to ensure that the national strategy being developed is flexible and responsive to individual's coping strategies and information choices.

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